EXPERIENCES AND PERCEPTIONS OF FIRST-TIME MOTHERS WHO CONCEIVED WITH ASSISTED REPRODUCTIVE TECHNOLOGY AND SUBSEQUENTLY HAD INFANTS WHO WERE ADMITTED TO THE NEONATAL INTENSIVE CARE UNIT

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ABSTRACT

Background: The evolution of modern reproductive technology and the use of assisted reproductive technology (ART) have increased dramatically worldwide, making pregnancy possible for many infertile couples. However, since ART was established and the prevalence of the utilization of ART treatment to achieve conception has increased and become more complex, one of the most important consequences has been premature births. As a result, an increasing number of women who have successfully conceived after undergoing ART give birth to preterm infants, and these infants, in all likelihood, require admission to and some length of stay in the neonatal intensive care unit (NICU) for special care after birth. Nevertheless, no study has focused on mothers who conceived as a result of ART treatments/procedures and who, subsequently, had infants that required admission to the NICU.

The purpose of this study was to explore the experiences, perceptions, and coping strategies of mothers who underwent ART and gave birth to infants who required admission to the NICU.

Method: A qualitative descriptive approach was used to explore the emic experiences, perceptions, and coping processes of ART first-time mothers when their infants were admitted to the NICU. This study employed open-ended questions to explore and interpret meaningful themes. The interview data were transcribed and analyzed using an iterative process in order to identify common themes.

Findings: Nine women meeting the inclusion criteria were recruited and enrolled in the study. Data analysis revealed four themes that reflected common perceptions and experiences of the participants. The participants in this study provided some new

information about these mothers' unique experiences and perceptions, as well as some similarities with the experiences of non-ART mothers whose infants had NICU stays. Many of the mothers indicated that undergoing ART was a really traumatic experience, and, for a few, having an infant in the NICU was a less traumatic experience because the ART treatment had created more intense feelings of distress. Some of the mothers stated that the exposure to the technology and procedures (e.g., injections) that were a part of their ART treatments helped their adjustment to having their infants in the NICU. Other mothers indicated that watching their infants experience injections and invasive procedures, or have routine equipment used to assess their well-being (e.g., monitors), was more uncomfortable and upsetting due to their ART experiences.

The new finding indicated that, for mothers who required ART treatment and had viable births but whose infants needed special care in the NICU, their experiences of stress and ways of coping focused on adapting to a new unfamiliar environment while transitioning to motherhood.

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION

The desire to have a child is an inexplicable instinct and part of human nature (Silva, 1997). Most American women expect and desire to have their own children because motherhood is often viewed as the most important life role a woman can assume (McQuillan, Stone, & Greil, 2007). However, not all women who desire to have children can attain this goal as part of the normal biologic process to conceive due to infertility issues. In general, infertility is defined as the inability of a couple to conceive naturally after one year of regular unprotected sexual intercourse (Kamel, 2010). In the United States (U.S.), approximately 12% of married women between 15 and 44 years of age are reported to have impaired fecundity (i.e., difficulty with conceiving and/or difficulty with carrying a pregnancy to live birth), and 6.7 % of women between 15 and 44 years of age are infertile (Center for Disease Control and Prevention [CDC], 2017).

In 1978, the very first baby in the world who was conceived through the use of in vitro fertilization (IVF) was born (Paulson, 2011). Shortly thereafter, in 1981, the first baby conceived with the use of IVF in the U.S. was born (Sunderam, Kissin, Crawford, Folger, Jamieson, Warner, & Barfield, 2015). Since then, the use of advanced technologies to overcome infertility has increased steadily in the U. S. (Sunderam et al., 2015).

The evolution of modern reproductive technology and the use of assisted reproductive technology (ART) have increased dramatically worldwide, making pregnancy possible for many infertile couples. The original precursor for ART was fallopian tube disease in women; this indication has now been expanded to include male factors (e.g., hypospermia), and female factors other than tubal disease, including endometriosis, ovulatory dysfunction, uterine factors, and unexplained infertility (Shaykh, 2000). As medical technologies have improved, the use of

ART procedures and their success rates have increased. In 2015, a total of 182,111 ART procedures were performed in the U.S., resulting in 59,334 births of 71,152 viable infants, accounting for approximately 1.7 % of U.S. births (Sunderam et al., 2018).

Undergoing ART treatment, however, is not easy. Often, ART is used as a last resort for infertile couples to create their own families. ART treatment is not only monetarily draining and time-consuming, but also an emotional and physical burden for both the woman and her partner (Eugster & Vingerhoets, 1999). Moreover, the increased expense of the various ART treatments that may be needed to successfully achieve a viable pregnancy is well known. "Because many ART cycles are not successful, the average cost per infant born ranges from $38,000 to $85,000" (Henne & Bundorf, 2008, p. 66). Although approximately 7% of the population is affected by infertility (CDC, 2017), the treatment option of ART remains unaffordable for the majority of infertile couples (Aleyamma, Kamath, Muthukumar, Mangalaraj & George, 2011). Despite this, many women undergo ART treatments to have children, since human beings possess the instinct to reproduce.

Statement of the Problem

The use of ART procedures improves fertility and gives new hope to infertile couples. However, the problems associated with the use of ART for both women undergoing the procedures to conceive and their infants were investigated over time in many studies. Nevertheless, no study has focused on mothers who conceived as a result of ART treatments/procedures and who, subsequently, had infants who required admission to the NICU.

The purpose of this study was to explore the experiences, perceptions, and coping strategies of first-time mothers who underwent ART and gave birth to infants who were

subsequently admitted to the NICU, thereby addressing a gap in the scientific literature about this vulnerable group of mothers.

Theoretical / Conceptual Framework

Mishel's (1988) *Uncertainty in Illness Theory*, Lazarus (1993)'s *Coping Theory*, and Folkman (2010)'s *Stress, Coping and Hope Theory* provide concepts that have been considered by the researcher during the process of developing the research study. During the researcher's analysis of the data collected, Mishel's *Uncertainty in Illness Theory* provided perspectives about the cognitive processes of the study participants' meaning of stressful events. Similarly, Lazarus' (1993)'s *Coping Theory* provided perspectives about the participants' responses and adaptations to stressful situations (e.g., transitioning to a new role, having an infant admitted to the NICU for care). Folkman's (2010)'s *Stress, Coping and Hope Theory* provided guidance during the analysis for this unique group of first-time mothers, since hope is the key element in adapting to coping with uncertainty and stress.

Research Questions

1. What were the experiences and perceptions of first-time mothers who received ART treatment and who gave birth to infants who required admission to the NICU?
2. How did these mothers cope with these experiences and perceptions?

Methodology

Study Design

This study used a descriptive qualitative research design. The researcher conducted face-to-face interviews using open-ended questions to inquire about ART mothers' perceptions about having given birth to infants requiring admission to the NICU. The interviews took place two to

four weeks after their infants were discharged from the NICU and required approximately one hour to complete.

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were developed and subsequently modified due to lack of enrollment in the study as a result of limitations in eligibility. The revised eligibility criteria for women were used to enroll all participants.

Mothers who met the following modified criteria were eligible to participate: 1) gave birth for the first time and underwent ART treatments/procedures to conceive; 2) gave birth to viable infants; 3) gave birth at Kapiolani Medical Center for Women and Children (KMCWC); 4) had infants who were admitted to the NICU; 5) had infants who stayed in the NICU at least one week after birth; 6) had infants who were in stable condition and close (within approximately a week) to being discharged to go home when the mothers consented to the study; 7) had infants who did not have congenital abnormalities; and 8) spoke English or Japanese (because the researcher is fluent in both languages).

The modified exclusion criteria for mothers were as follows: 1) underwent ART treatment/procedures to conceive but did not give birth to viable infants; 2) were multiparous; 3) did not give birth at KMCWC; 4) underwent ART treatment/procedures to conceive, but had infants who were not admitted to the NICU; 5) had infants who were discharged after less than one week in the NICU; 6) had infants who were critically ill and/or in unstable condition; 7) had infants with multiple congenital abnormalities or long-term problems such as gastrostomy tube (GT) placement and/or tracheotomy; 8) did not speak English or Japanese; and 9) were not willing to be interviewed.

Sample and Recruitment

The study used purposive sampling in order to enroll participants who had experienced the critical elements of the study, specifically, who were first-time mothers who underwent ART to conceive and who subsequently gave birth to infants admitted to the NICU. Based on the qualitative methodology being used, it was initially estimated that 15 to 20 participants would be needed in order to achieve saturation. However, saturation was reached after completing nine interviews, so recruitment ended. Potential participants were identified when the mothers' infants were receiving care in the NICU. Eligible participants were identified by the EPIC Information Technology (IT) teams at KMCWC on a weekly basis through a review of the KMCWC electronic medical record (EMR) system using ICD-10 Codes to identify possible participants. The researcher was notified about these potential participants by the EPIC IT team and subsequently went to the NICU to recruit participants who met the inclusion criteria.

Setting

Participants were recruited at the KMCWC. The KMCWC is Hawai`i's only tertiary maternal, newborn, and pediatric specialty medical center for the Pacific Basin.

Protection of Human Subjects

An application to the University of Hawai'i at Manoa (UHM) Committee on Human Subjects (CHS) and the KMCWC institutional review board was submitted. Once approval from both of these entities was received, eligible participants were identified. Women who indicated an interest in participating in the study were informed about the purpose of the study and the procedures that followed, including reviewing and signing an informed consent document, providing a contact number for the researcher, and establishing a tentative study visit (which the researcher confirmed with the mother after the infant was discharged from the hospital).

Participants were told that participation in the study was entirely voluntary, they had the right not to answer any questions that made them feel uncomfortable, and they were free to refuse to participate and could withdraw from the study at any time without this having any impact on their care or their infant's care at KMCWC.

Data Collection and Management

Data collection strategies included the completion of a demographic questionnaire by the participants, and individual, face-to-face interviews using open-ended questions. The interviews were audio recorded and transcribed by the researcher. Participants received a study number that was used to identify data and protect the participants' privacy. The audiotapes of the interviews and other study documents were kept in a locked file that was separate from the locked file where the participants' signed informed consents were kept. Audiotapes and transcripts will be destroyed after completion of the study per current UHM CHS requirements.

Data Analysis

Descriptive statistics were used to analyze demographic data collected. The interview data were transcribed and analyzed using an iterative process in order to identify common themes.

Results

Nine women meeting the inclusion criteria were recruited and enrolled in the study. The mean age of the mothers was 37.9 years, with a range of 29 to 46 years. All were married. Six participants identified their race/ethnicity as being Asian (five of Japanese descent and one of Chinese descent), and three identified as White. More than half (N=5) had completed higher levels of education (master's degrees). The majority of the mothers resided on Oahu (N=8), and one mother resided on Maui.

A total of 25 codes were identified, with eight categories emerging from the codes. Further analysis revealed four themes that reflected common perceptions and experiences of the participants: *Fear of uncertain outcomes, A whole new world, Gaining knowledge as a coping mechanism, and Journey to become mothers*.

Discussion

Data analysis revealed four themes that reflected common perceptions and experiences of the participants. *Fear of uncertain outcomes:* Uncertainty was a central theme for mothers who desired infertility treatment to conceive, and the uncertainty continued when their infants required admittance to the NICU. The lack of familiarity with the environment and an unfamiliar routine stimulated fear of uncertain outcomes. *A whole new world*: The length of the infants' NICU stay affected the mothers' psychological status because the length of the NICU stay applied not only to the infants' conditions, but also to the mothers' routine to develop and adapt to their new environment in the NICU. They felt the need to create some type of comfortable environment in an unfamiliar place where they were not allowed to fully take care of their infants and relied on the NICU staff to meet most of their infants' needs. *Gaining knowledge as a coping mechanism:* The information provided by the NICU team made them feel more at ease, and the knowledge mothers gained appeared to be a useful tool to cope with their uncertainty and stress about their infants' well-being. *Journey to become mothers:* Undergoing the ART process impacted the mothers' psychological status while their infants were in the NICU, which reflected various coping strategies to deal with stress and uncertainty during this time in order to successfully transition to motherhood.

Strengths and Limitations of the Study

This was the first study that was designed and conducted to address the perceptions and experiences of mothers who had undergone successful ART treatment and pregnancies and, subsequently, had their infants admitted to the NICU. All the participants who met the inclusion criteria had similar socioeconomic statuses and educational backgrounds. However, this research had a very small selective group of women utilizing services at a hospital in Hawai`i that specialized in maternal-child care. For example, studies conducted in more heterogeneous populations in different settings and/or cultures may reveal different findings.

Conclusion

The participants in this study provided some new information about these mothers' unique experiences and perceptions, some of which were similar to the experiences of non-ART mothers whose infants had NICU stays. However, the study indicates some new findings about mothers who required ART treatment and had viable births, but whose infants needed special care in the NICU. Their experiences of stress and ways of coping focused on adapting to a new unfamiliar environment while transitioning to motherhood.

CHAPTER 2: LITERATURE REVIEW

The purpose of the literature review was to investigate and gain insight into the experiences and perceptions of first-time mothers who received ART treatment and gave birth to infants requiring admission to the NICU. This review was done to provide background for developing a study to explore the issues surrounding mothers who underwent ART to conceive.

Review of the Literature

Search Strategies

An initial review of the literature was conducted from 2011 until 2016, with a subsequent review conducted in 2019. The subsequent review yielded no new studies meeting the research terms described in the following sections (i.e., all literature reviewed for the study was a result of the 2011 to 2016 searches).

The electronic databases PubMed, the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Cochrane Library, and PsycInfo were searched using the terms "assisted reproductive technology," "IVF," "postpartum depression," "NICU," and "motherhood." First, a search was conducted with the key words "IVF OR assisted reproductive technology AND postpartum depression AND the neonatal intensive care unit OR NICU," but no articles were identified using these terms in PubMed. Consequently, the definitions and terms were modified. The search topics were stratified to address the following: first-time mothers who conceived with assisted reproductive technology and were at risk of postpartum depression after delivery; and second, mothers of NICU babies and postpartum depression and/or transition to motherhood. Using the key words "IVF OR assisted reproductive technology AND postpartum depression," 39

articles were found. The key words “IVF OR assisted reproductive technology AND NICU” resulted in an additional 83 articles. The key words “neonatal intensive care unit AND motherhood” resulted in 13 articles. Within these results, the titles and abstracts of each of the 135 citations were reviewed. “Related articles” and “review” were also checked to find additional studies on the same topics. Finally, reference lists of articles were searched for other relevant articles. Of 135 articles, 30 articles met the criteria and were included in the in-depth review. The rest of the articles focused more on the technique/procedure of ART or did not discuss maternal and/or infant health. Therefore, 105 articles were excluded.

Selection of Studies for Review

Articles focusing on psychological/physiological aspects relating to ART treatment and/or focusing on babies in the NICU conceived by ART or multiple gestations as a result of ART treatments were included. Publications that were in English or Japanese and had an abstract with full text were included. Published articles addressing merely the procedure; ovarian problems; single, lesbian, or bisexual mothering or gay parents; surrogacy; donor eggs/sperm; and pre-implantation genetic diagnosis were excluded. Publications that were not written in English or Japanese and that were without full text were also excluded. The technologies of ART have been used since 1978 in England, and the first live birth was reported in the U.S. in 1981. To understand the historical flow of ART, literature was searched without a timeframe.

Of the 30 articles that met inclusion criteria for this literature review, 16 addressed psychological aspects of ART treatment, and four addressed ART and postpartum depression with multiple births. Five addressed ART and parenthood. One article

addressed ART and multiple births, and two addressed the relationship between NICU and motherhood or parenthood. Only one reported an investigation of marital relationships and transition to parenthood with ART, and another one described preterm birth and low birth weight among ART singleton births.

The majority of the articles (24 of the 30) were published internationally: seven in Australia; three in Canada; two each in Italy, Finland, Denmark, and Portugal; and one each in Turkey, Israel, Switzerland, Netherlands, the United Kingdom, and Taiwan. Six of the 30 articles were published in the U.S.

Since ART has been used worldwide, the Literature Review Matrix table (refer to Appendix A) was organized into two sections, international studies and U.S. studies. The studies are listed in chronological order.

Synthesis of Selected Studies

The purpose of this synthesis of the literature was to explore the recent research about the topic with a broader focus beyond ART procedures used to achieve pregnancy and to delve deeper into other issues (e.g., psychological impact) surrounding ART. It was also done to identify any research that was completed that addressed the experiences and/or perceptions of first-time mothers who conceived using ART and subsequently gave birth to infants requiring NICU admission.

The Main Concepts

Based on the literature review, the main critical concepts that were chosen were infertility, ART, and transition to parenthood when infants were admitted to the NICU. Furthermore, this review extended beyond the technological and medical aspects to gain knowledge about deeper issues surrounding infertility, ART, and parents of NICU infants

(e.g., psychological impact of this experience on mothers). Motherhood was originally one of the concepts for this review, but many articles focused on "parenthood" rather than "motherhood." Thus, in this review, the concept was modified to parenthood.

Infertility. Infertility is defined as an inability of a couple to conceive naturally after one year of regular unprotected sexual intercourse (Kamel, 2010). It is a problem for a significant percentage of people, affecting approximately 10% of women of childbearing age globally (Ross, McQueen, Vigod, & Dennis, 2011). "Infertility by itself does not threaten physical health but has a strong impact on the psychological and social well-being of couples" (Forti & Krausz, 1998, p. 4187). Some women view infertility with feelings of insecurity, surprise, and failure in their gender role (Sarantaki, Gourounti, & Lykeridou, 2008). In some situations, infertility is deeply feared and a woman's status and security can be affected (Widge, 2005).

McQuillan et al. (2007) surveyed a randomly selected sample of 580 Midwestern women, aged 25 to 55, to determine the relationship between infertility and their perceptions of life satisfaction. Of these 580 women, 196 (34%) met the study's criteria for a diagnosis of infertility. Of these 196 women, 69 (35%) perceived that they had experienced fertility problems, while the remaining 127 women did not perceive any problems. Their study results found that there is no direct correlation between lifetime infertility and life satisfaction, regardless of a woman's perception of fertility problems. The results also indicated that a history of infertility in itself does not lower a woman's life satisfaction. However, they found that "there is a strong association between motherhood and marriage" ($r = .30$, $p < 0.001$)" (p. 974). However, for married infertile

women in particular, those who did not have children perceived a lower life satisfaction (McQuillan et al., 2007).

Among the international articles, a cohort study conducted in 2010 in Turkey examined the relationship between infertility and postpartum depression (PPD) (Akyuz, Seven, Devran, & Demiralp, 2010). This study recruited 51 fertile and 105 infertile women from two different hospitals in Turkey. The researcher developed a "Descriptive Information Questionnaire" and also adapted two other scales, the "Beck Depression Inventory" and the Turkish version of Beck's "Postpartum Depression Screening Scale," to collect the data. The infertile group included all women who conceived after treatment for primary infertility, and the fertile group consisted of primiparous women without any history of infertility who conceived spontaneously. Women whose Beck Depression Inventory points were more than 17 during the last trimester were excluded because these women were already reporting depressive symptoms during pregnancy. The researcher concluded that a history of infertility is not a major factor in PPD, but a history of depression prior to childbearing may contribute to its development during pregnancy and/or the postpartum period (Akyuz et al., 2010). Thus, the results suggest that infertile women who do experience severe anxiety and stress prior to ART could be more prone to develop depression during or after pregnancy, and should, therefore, be monitored closely.

Assisted reproductive technology. For over three decades, ART has been used worldwide to treat infertility, create new hopeful possibilities, and provide couples with the opportunity to have their own children. The number of uses of ART has been increasing worldwide. For example, in England, women used ART treatment to conceive

four times more in 2006 than in 1992 (Fisher et al., 2013). Moreover, in Australia, ART births increased from 1.5% in 1998 to 3.2% in 2008 (Fisher et al., 2013).

In many cases, ART will fulfill the wishes of infertile couples; however, it may also create the potential risk "for a divide between the physiologic and psychological aspects of procreation" (Monti, Agostini, Fagandini, La Sala, & Blichstein, 2009, p. 851). ART involves a significant physical, financial, and emotional commitment on the part of the couple. In general, much research has focused on the technological aspects of ART and its outcome, including multiple pregnancies. In fact, until 1999, few prospective studies of mothers who had undergone ART addressed the psychosocial and psychobiological impact of ART on the woman (Eugster & Vingerhoets, 1999). However, over time, more research has focused on the psychological and social aspects of ART (Akyuz et al., 2010; Cox, Glazebrook, Sheard, Ndukwe, & Oates, 2006; Darwiche et al., 2014; Gameiro, Moura-Ramos, Canavarro, & Soares, 2010; Hammarberg, Fisher & Wynter, 2008; Harf-Kashdaei & Kaitz, 2006; Lee, Liu, Kuo & Lee, 2011; Lewis, Liu, Stuart, & Ryan, 2013; Listijono, Mooney & Chapman, 2014; McMahon, Ungerer, Tennant, & Saunders, 1997; McQuillan et al., 2007; Monti, Agostini, Fagandini, La Sala, & Blichstein, 2008; Monti et al., 2009; Raguz, McDonald, Metcalfe, O'Quinn, & Tough, 2014; Ross et al., 2011; Schmidt, 2009).

The relationship between ART, the risk of postpartum depression, and the quality of the mother-child relationship, including the transition to parenthood, has been studied in Australia, Canada, Italy, Portugal, Israel, and the U.S. (Fisher, Hammarberg & Baker, 2005; Gameiro et. al., 2010; Hammarberg et al., 2008; Lee et al., 2011; Lewis et al., 2013; Listijono et al., 2014; Harf-Kashdaei & Kaitz, 2006; McMahon et al., 2011;

McMahon et al., 1997; Monti et al., 2008; Monti et al., 2009; Ross et al., 2011). From these studies, researchers hypothesized that women who conceive using ART and women with multiple births may be at an increased risk of developing postpartum depression (Ross et al., 2011). One Italian case-control longitudinal study focused on assessing the relationship between women who conceived through ART and depressive symptoms during late pregnancy and early parenthood. They recruited 87 mothers, including 48 ART couples (25 mothers and 23 fathers), and 39 non-ART mothers. The mothers were evaluated with the Edinburgh Postpartum Depression Screening (EPDS) scale at 30 to 32 weeks of gestation, and at one week and three months after giving birth. The study found that women who conceived after ART were more emotionally vulnerable and showed higher mean EPDS scores than non-ART mothers at the third trimester of pregnancy (7.88 vs. 4.32, $p < .0005$), at one week (8.0 vs. 4.89, $p < .005$) and at three months after giving birth (5.76 vs. 3.87, $p < .05$). (Monti et al., 2009). However, when they assessed the frequency of the depressed mothers, ART mothers showed a significantly higher rate than non-ART mothers only at the third trimester of pregnancy ($p = .02$), and there was no significance between them at one week and three months after giving birth (Monti et al., 2009).

In a systematic review in Canada and Australia, Ross et al. (2011) and Listijono et al. (2014) found no evidence that women who conceived following IVF treatment were at increased risk of PPD relative to those who conceived naturally. Moreover, a high socioeconomic profile is characteristic of women using ART to conceive, and, therefore, the risk for PPD in this population is lower compared to women from lower socioeconomic levels giving birth (McMahon et al., 2011).

The use of ART is associated with an increased incidence of health problems for mothers, including higher rates of caesarean births, maternal hemorrhage, pregnancy-induced high blood pressure, and gestational diabetes, and as well as for the infants, such as prematurity, low birth weight (LBW), death, elevated risks for birth defects, and disabilities (Sunderam et al., 2015). Studies conducted in Denmark and Canada have found associations between having undergone an ART procedure to conceive and an increased risk of having a LBW infant at term, prematurity, and infant admittance to the NICU (even in pregnancies with a single fetus) (Wisborg, Ingerslev & Henriksen, 2010; McDonald et al., 2009). In addition, the chance of multiple pregnancies is increased in ART procedures when more than one embryo is transferred (Ross et al., 2011). Although some would consider twins a happy result, there are many problems associated with multiple births, and the problems become progressively more severe and common with triplets or a higher number of multiple fetuses. In addition, infants conceived as a result of ART may be born early and are at risk of developing disabilities (e.g., neurodevelopmental disorder, which is difficulty with social interaction, communications and/or learning disorder) as a consequence of prematurity (Melnyk & Feinstein, 2009).

Four articles studied the relationship between ART and multiple births and parental psychological adjustment. Three studies, conducted in Australia, Canada, and Finland, focused on the relationship between multiple births and PPD (Hansen et al., 2009; Ross et al., 2011; Vilska et al., 2009). In the Finland study, the risk of maternal depression was increased at six weeks postpartum in ART mothers who gave birth to twins and triplets, compared to ART mothers who had singleton births (Vilska et al., 2009). One of the major factors contributing to multiple births following ART procedures is multiple

embryos transferred per cycle (Henne & Bundorf, 2008). Therefore, transferring a single embryo can reduce the multiple birthrate and consequent poor perinatal outcomes associated with multiple embryo transfer ART procedures (Hansen et al., 2009).

However, it is important to keep in mind that in some countries (e.g., Australia) universal healthcare coverage pays for a proportion of the costs for what appears to be an unlimited number of ART treatment cycles (Fisher, Hammarberg & Baker, 2008). In fact, studies have found that state-mandated insurance coverage is associated with a 277% increased utilization of ART procedures/treatments (Jain, Harlow & Hornstain, 2002). As the cost per cycle is high, patients without insurance face strong financial incentives to minimize the total treatment cost by successfully conceiving in fewer cycles (Henne & Bundorf, 2008). Thus, the relationship between ART, psychological and psychosocial issues, and risk of adverse perinatal outcomes could vary depending on medical coverage and the number of ART cycles, a woman must undergo to achieve a successful pregnancy.

In the U.S., motherhood is regarded as a social norm and gendered expectations influence women to become mothers (McQuillan et al., 2007). Social roles have strong associations with women's lives. However, women are not all alike and, therefore, have different life experiences and expectations. Several current social trends, such as marriage later in life, improvements in contraception and access to family planning, increased education, women focusing on establishing successful careers, and greater numbers of women in the work force, can contribute to women's "infertility." In general, society views womanhood as synonymous with motherhood, and becoming pregnant is vital to fulfilling a woman's role (Sarantaki et al., 2008).

A recent study investigated the postpartum mental health outcomes of mothers who conceived using fertility treatment (Raguz, et al., 2014). The research recruited 1,654 pregnant women who received prenatal care in Calgary, Alberta. Of the 1,654 women, 76 were identified and selected as the study group. These women received various fertility treatments, including fertility drugs to induce ovulation (Clomid, Serophine, Gonal-F, etc.), artificial insemination (AI), intrauterine insemination (IUI), ART (including IVF), intracytoplasmic sperm injection (ICSI), fresh embryo transfer, donor embryo transfer, and superovulation/IUI (Raguz, et al., 2014). One hundred and fifty-two women who did not receive fertility treatment were randomly selected as the control group. However, this study included only women who gave birth to a single infant and excluded women with multiple births. The results of the study found that at four months postpartum, there were no statistically significant differences between the two groups of women in terms of their postpartum mental health such as depression, anxiety, or perceived stress (Raguz, et al., 2014).

In another study conducted in the Netherlands, Warmelink et al. (2012) conducted a cross-sectional study of 428 mothers to determine differences in psychological symptoms between women who underwent ART procedures and women who conceived without ART interventions. The results indicated that there were no significant differences in the prevalence of post-traumatic stress disorder (PTSD), anxiety, and depression in ART mothers compared with mothers who conceived naturally.

Similar to the findings of Raguz et al. (2014) and Warmelink et al. (2012), cross-sectional studies conducted in Australia and the U.S. also found that there were no increased risks for PPD among women who conceived using ART procedures compared

with women who conceived naturally (Listijono et al., 2014 & Lynch, & Prasad, 2014). Another study using a prospective cohort design evaluated whether older (≥37 years) first-time mothers (n=189) have higher rates of PPD compared with younger (<37 years) first-time mothers (n=387) and found that there were no significant differences in increased vulnerability to postnatal depression in older first-time mothers whether conceiving through ART or spontaneously (McMahon et al., 2011). In addition to this review of the literature, only one study (Raguz, et al., 2014) mentioned included mothers who received various types of treatment of ART; however, there were no distinguishing results regarding the types of ART.

Transition to parenthood. "Becoming a parent is among the major interpersonal transitions during adulthood for both genders" (Repokari et al., 2005, p. 3238). "Infertility, ART treatment, and parenthood are experiences that people usually go through as couples" (Gameiro, Moura-Ramos, Canavarro, Santos, & Dattilio, 2011, p. 103). In 1997, a prospective, longitudinal study was conducted in Sidney, Australia by McMahon et al. that explored the psychosocial adjustment of mothers who conceived by ART and their cognitive and emotional development. The subjects included 65 women who underwent ART to conceive (the study group), and their results were compared to 62 women who conceived naturally (the control group). The results did not demonstrate a major difference in psychosocial adjustment between the control and study groups. However, the study did find some evidence of minor difficulties experienced by some women, including evidence of lower self-esteem in terms of perceptions of womanliness and sexuality in the study group, which may have been a result of unsettled emotional or psychological feelings linked to their infertile status.

Moreover, the study also found that the mothers who conceived by ART expressed lower self-efficacy regarding their maternal role in relating to their infants' care (including entertaining their infants and settling [e.g., comforting] their infants). Furthermore, the study indicated that the repeated-cycle ART groups reported significantly ($F = 6.91$, $df = 1,117$, $P = 0.010$) lower perceptions of self-efficacy. Interestingly, ART mothers perceived their infants to be fussier (difficult temperament) than the control group, although their infants' temperament difficulty was "within the normal range when compared with Australian normative data for this age" (p. 492). These results suggested that there could be some underreporting of distress by women giving birth through ART because these mothers may have high expectations for themselves after achieving their goal of giving birth to a long-awaited infant. Therefore, the study suggested that increased emotional support in the early postpartum period for mothers who conceived by ART might promote overall maternal postpartum mental health (McMahon et al., 1997). However, several years later, in a prospective longitudinal study in Finland, Repokari et al. (2005) conducted a study to explore if there are any differences in mental health status during the transition to parenthood between ART parents and non-ART parents. They recruited 367 couples with a singleton conceived with ART (study group) and 379 couples with a spontaneous singleton (control group). They found that successful ART did not predict depressive symptoms during transition to parenthood in the study group and there was no negative impact on maternal social and child-related stress during the transition to parenthood. The researchers noted that this result could reflect the ART couples' "satisfaction with successful treatment and fulfillment of hope for parenthood" (Repokari et al., 2005, p. 3245).

A study conducted by Fisher et al. (2005) in Melbourne, Australia investigating the effects of ART conception on parenting found contrary results compared to those of McMahon et al., and Repokari et al. Fisher et al.'s study audited 745 medical records from a mother baby unit at a private hospital in Melbourne and found that women giving birth after conceiving as a result of an ART procedure had a significantly (relative risk 4.0; 95% confidence interval, 3.0-5.4) increased rate of early parenting difficulties such as "mild to moderate maternal depression and anxiety and unsettled infant behavior" (p. 429) and were more likely to be admitted with their infants to residential early parenting centers for treatment.

Fisher et al. (2008) subsequently conducted a quantitative prospective, longitudinal study to investigate the determinants of antenatal mood disturbances and other risks for early parenting difficulties after ART. One hundred and eighty-three women undergoing ART were recruited when they conceived and were followed until 18 months postpartum. Women were contacted by telephone and completed interviews and self-report questionnaires, including the EPDS, the Antenatal Attachment Questionnaire (AAQ), the Intimate Bonds Measure (IBM), and the Vulnerable Personality Style Questionnaire (VPSQ). The results of the study revealed that mother-to-fetus attachment scores were much higher in ART mothers than the general sample. Their findings also indicated that ART mothers had significantly better pregnancy mental health, quality of relationship with their partners, and higher emotional attachment to their unborn babies than the general population. However, the study found that women who had higher EPDS scores in early in pregnancy were significantly more likely to have higher late pregnancy EPDS scores, which indicated that these women probably had chronic mood disturbances.

It is possible that in pregnancies after ART procedures, parenthood is idealized, leading to the development of a confident parental identity (Hammarberg et al., 2008). It seems that ART treatment itself does not cause deterioration of parenting behaviors, but the nature of the ART procedure, preexisting maternal mood disorders, and high expectations for an optimal outcome of the ART procedures (e.g., a normal singleton birth at term) might affect parenting. Thus, it is important to offer parents who have ART additional psychological and psychosocial support, as this may facilitate their transition to parenthood.

Since the establishment of the NICU in the early 1970s, advances in neonatal intensive care have improved the survival of high-risk preterm and critically ill infants (Stewart, 2011). A NICU admission itself is "a stressful time for which most families typically have not had the opportunity to prepare" (Howland, Pickler, McCain, Glaser & Lewis, 2011, p. 91). Delivering a premature infant could contribute to an extremely stressful, confusing, and difficult time for parents (Brett, Staniszewska, Newburn, Jones, & Taylor, 2011). Preterm birth results in a multitude of negative outcomes for infants, including extended stays in the NICU; developmental delays; physical, mental health, and behavioral problems; increased medical utilization; and poor academic performance (Melnyk & Feinstein, 2009). Hence, evidence of potential parental stressors should be carefully monitored by clinicians because maternal stress can have deleterious effects on mother-infant interactions, particularly on the mother's abilities to form an attachment to her infant. Ultimately, abnormal or delayed maternal-infant attachment can affect the cognitive, emotional, and social developmental outcomes of the child (Trombini, Surcunelli, Piccioni, Alessandroni, & Faldella, 2008).

Prior to 2004, the psychological and social implications of multiple fetuses following ART treatment had not been well studied (Klock, 2004). However, by 2009 a number of studies investigated the parental stress and anxiety experienced by mothers of multiple births conceived through IVF (Choi, Bishani & Minkovits, 2009; Hansen et al., 2009; Vilska et al., 2009). A study, conducted in the U.S., found that mothers of NICU babies are often delayed in establishing their maternal role (Shin & White-Traut, 2007). Another study of parents of preterm infants who were provided with an educational-behavior intervention program to teach them about their premature infants' behaviors, as well as parenthood, indicated that parents who have preterm infants experience a higher incidence of depression and anxiety disorders if they are not provided appropriate parental education and psychological support (Melnyk & Feinstein, 2009).

Finally, a study in Portugal found that marital status, PPD, and transition to parenthood are strongly linked; and if a couple has a better marital relationship and marital congruence, the couple's ability to cope with stressful or demanding events increases (Gameiro et al., 2011). Thus, in order to better help mothers and couples transition to parenting roles when they have undergone ART procedures to conceive and have infants admitted to the NICU, it is important to consider how the couple as a unit perceives, is affected by, and reacts to the experience of their infant being in need of special care in the NICU (Gameiro et al., 2011). The assessment of the marital relationship and their congruence as a couple can help clinicians develop strategies to support parents' transition to parenthood, especially those whose infants are admitted to the NICU.

Critique of Selected Studies

Overall Strengths of the Studies

The literature review clearly revealed that the evolution of modern reproductive technology and the use of ART have increased dramatically worldwide. In addition, it provided evidence that the relationship between ART, the risk of postpartum depression, and the quality of the mother-child relationship, including the transition to parenthood, has been investigated over time in many studies. Therefore, the psychological impact of infertility has been widely confirmed and many manifestations of psychological disorders in infertile women have been reported. The use of ART procedures improved fertility and gave new hope to infertile couples; however, the problems associated with the use of ART for both women undergoing the procedures to conceive and their infants were also well documented.

The studies also indicated that undergoing ART procedures increases perceptions of maternal uncertainty. In addition, the procedure involves a significant physical, financial, and emotional commitment on the part of the infertile couple. Several studies revealed psychological stress to be a common problem associated with ART procedures and concluded that providing education and identifying and using resources to provide support could be useful to enhance mothers' coping strategies and, thereby, promote optimal postpartum adjustment.

Limitations of the Studies

Many studies that were included in this review addressed ART treatments/procedures and the possible psychological effects on women and couples who have undergone these procedures. Nevertheless, no study focused on first-time mothers

who conceived as a result of ART treatments/procedures and who, subsequently, had infants who required admission to the NICU.

There have been several studies of ART-treated mothers, including qualitative studies designed to explore how mothers describe their feelings even after the success of ART treatment. The results, however, were inconsistent, and the strength of any associations remains to be confirmed due to the differences in the study designs, the variation in the number of women participating in the studies, and the different countries in which the studies were conducted. Moreover, a number of studies were conducted in countries where full or partial healthcare coverage for infertility treatments is provided by the government, which is not the situation in the U.S. Therefore, extrapolating the findings of these studies to women in the U.S. who undergo fertility treatments has to be done with caution. Also, there were questions that remain unanswered and require further research in order to address how those mothers and couples who have undergone ART treatment/procedures to conceive and have an infant requiring admission to a NICU cope with this situation as they transition to parenthood. None of the studies reviewed addressed this particular situation.

Another major limitation of the studies reviewed was that the majority did not include information about the health status of the infants. If some of the mothers who had conceived via ART treatments/procedures gave birth to disabled or ill infants, then some of the conclusions without information about the infants' health could be incorrect, especially for those studies that found increased rates of PPD, anxiety, and delayed-maternal infant attachment behaviors, because it could cause bias in the interpretation of the results. Finally, the deterioration of marital quality among couples who have

undergone ART treatment/procedures that resulted in the birth of a first child with a disability needs to be investigated.

Theoretical/Conceptual Framework

Becoming a mother alone is a dynamic life change for women psychologically and physically, especially after the treatment of infertility. However, the process is often stressful, and there is not 100% certainty that the desired outcome (i.e., a healthy child) will result. *Uncertainty* is a central theme for mothers who desire infertility treatments to conceive. Multiple areas of uncertainty can be experienced, including whether or not they will be able to conceive, have a full-term pregnancy, deliver a healthy infant, and be able to care for multiple infants (e.g., twins, triplets) and/or a premature infant. According to Mishel (1983), "Uncertainty is a perceptual variable and occurs in situations where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes" (p. 356).

Mishel's Uncertainty in Illness Theory is the middle-ranged nursing theory that conceptually serves to explain how persons cognitively process illness-related stimuli and construct meaning in these events. If the person is dealing with uncertainty, it can indicate that the person is unable to construct meaning of stressful events (Mishel, 1988). Three contextual domains influence the theory: the antecedents of uncertainty, the process of uncertainty appraisal, and coping with uncertainty (Mishel, 1988). Moreover, the level of uncertainty will increase when there is ambiguity and/or unfamiliarity regarding the event(s), lack of information about the situation, and unpredictability in regard to the treatment and/or prognosis (Mishel, 1988).

Uncertainty involves psychological stress (Folkman, 2010). For people who are

coping with uncertainty and under serious and prolonged psychological stress, hope is the key element in adaptation to the event that stimulated the uncertainty (Folkman, 2010). Folkman (2010) also indicated that each stressful situation involves some degree of uncertainty, including *temporal uncertainty* (when something will happen), *event uncertainty* (what will happen), *efficacy uncertainty* (what can be done), and *outcome uncertainty* (the outcome). When people are experiencing internal and/or external stressful events to overcome, *coping* (a person's thoughts and behavior) will occur (Folkman, 2010).

There are two different types of coping with stress and uncertainty: problem-focused and emotion-focused (Folkman, 2010; Lazarus, 1993). Problem-focused coping occurs when a person confronts the "problem causing distress using strategies such as information gathering and decision making" (Folkman, 2010, p. 902). According to Lazarus (1993), problem-focused coping is used to change "the troubled person-environment relationship by acting on the environment or oneself" (p. 238). Emotion-focused coping involves a process "to regulate negative emotion using strategies such as distancing, seeking emotional support and escape-avoidance" (Folkman, 2010, p. 902). In other words, the person who is experiencing stress can cope by changing the stressful relationship within the environment or alleviating the relational meaning of the stress (Lazarus, 1993).

Coping is a key concept for adaptation to a stressful situation and/or transitioning to a new role (Lazarus, 1993). If a person who is experiencing uncertainty and stress can proceed through the coping strategy successfully, then adaptation will occur (Mishel, 1988). In the situation of first-time mothers who have undergone ART to conceive and

subsequently have an infant needing admission to the NICU, allowing them to verbalize feelings of uncertainty can allow healthcare providers to assist them in obtaining social support and other resources that can facilitate their successful adaptation to motherhood and attachment to their infant.

Gaps in the Literature

There were no studies reviewed that addressed the experiences or perceptions and coping processes of first-time mothers who used ART treatment to conceive and who gave birth to infants admitted to the NICU.

Summary

The literature review found that the use of ART treatment alone does not seem to cause deterioration of post-partum maternal mental health. However, multiple births have been correlated with an increased risk of PPD in mothers. This may be a result of the association of multiple births and prematurity, which contributes to infants being admitted to the NICU for special care. Studies also have revealed a relationship between having an infant admitted to the NICU and the development of PPD and anxiety in their parents. Nevertheless, no study addressed the transition to parenthood of women who underwent ART treatments/procedures to conceive and subsequently gave birth to infants requiring admission to the NICU.

Providing an opportunity to address uncertainty was an important process in eliciting social support, especially in women who had undergone ART and were having doubts about the pregnancy or desire for motherhood. It was important to determine the impact of such experiences and perceptions on maternal post-partum mental health in order to identify successful coping strategies in order to try to reduce the stress that can

be a result of perceptions of uncertainty. Interventions that could assist with successful coping include providing appropriate education (e.g., anticipatory guidance), identifying social support systems, and treatment to improve the psychological health of the mothers while facilitating attachment to their infants. Therefore, future research was needed to explore this gap in our knowledge about this population of mothers in order to develop strategies to ensure their health will be maintained or improved, and that they will successfully transition to parenthood while coping with an infant in the NICU.

There was a lack of scientific information about this group of mothers and their perceptions of uncertainty, stress, psychological symptoms, and how they cope with this situation as they transition to parenthood. Research was needed to address this gap in knowledge about this group of mothers. Based on the lack of scientific evidence addressing this topic, a qualitative approach was a first step to begin to address it. The purpose of this study was to explore the experiences, perceptions, and coping strategies of mothers who had undergone ART and gave birth to infants who required admission to the NICU. The study used an emic approach and employed open-ended questions in order to explore and interpret meaningful themes.

Research Questions

Based on the results of the review of the literature and an identified gap in the existing scientific literature, the research questions were as follows:

1. What were the experiences and perceptions of first-time mothers who received ART treatment and who gave birth to infants who required admission to the NICU?
2. How did these mothers cope with these experiences and perceptions?

CHAPTER 3: METHODOLOGY

As noted in Chapter 2, there was a lack of scientific information about the experiences, perceptions, and coping strategies of mothers who had undergone ART to conceive and gave birth to infants requiring admission to the NICU. Therefore, research was needed to address this gap in knowledge about this group of mothers. Therefore, the research questions were:

1. What were the experiences and perceptions of first-time mothers who received ART treatment and who gave birth to infants who required admission to the NICU?
2. How did these mothers cope with these experiences and perceptions?

Methods

Study Design

A qualitative methodology, specifically a qualitative descriptive approach, was used to investigate ART first-time mothers' experiences and perceptions of, as well as their coping processes about, having their infants admitted to the NICU. Due to the identified gap in the scientific literature about this topic, a qualitative approach was an appropriate methodology because this study was a first step in exploring the mothers' experiences, perceptions, and coping processes, given their unique situation and an existing gap in the scientific literature.

An emic perspective was used in an attempt "to capture participants' indigenous meanings of real-world events" (Yin, 2011, p. 11) in this study. Participants were interviewed face-to-face using open-ended questions so that they could answer questions in their own words. This provided an emic perspective about this experience. An emic

view is the insiders' (i.e., participants') viewpoints (Streubert & Carpenter, 2011) that allows the researcher to gather themes, patterns, and concepts about the participants' experiences.

Sample

The study used purposive sampling in order to enroll participants who had experienced the critical elements of the study. Specifically, they were first-time mothers who had undergone ART to conceive and who subsequently gave birth to infants admitted to the NICU. Based on the qualitative methodology being used, it was estimated that 15 to 20 participants were needed in order to achieve saturation.

Inclusion and Exclusion Criteria

Initial eligibility criteria were developed and subsequently modified due to lack of enrollment in the study as a result of limitations in eligibility. The revised eligibility criteria for women were used to enroll all participants.

Mothers who met the following initial criteria were eligible to participate: 1) gave birth for the first time and underwent ART treatments/procedures to conceive; 2) gave birth to viable infants; 3) gave birth at KMCWC; 4) had infants who were admitted to the NICU; 5) had infants who stayed in the NICU more than one month but less than three months; 6) had infants who were in stable condition and close (within approximately a week) to being discharged to go home when the mothers consented to the study; 7) had infants who did not have congenital abnormalities; and 8) spoke English or Japanese (because the researcher is fluent in both languages).

The following were the initial exclusion criteria: 1) first-time mothers who underwent ART treatment/procedures to conceive but did not give birth to viable infants;

2) first-time mothers who underwent ART treatment/procedures to conceive but who used donor eggs; 3) mothers who were multiparous; 4) mothers who did not give birth at KMCWC; 5) first-time mothers who underwent ART treatment/procedure to conceive, but whose infants were not admitted to the NICU; 6) mothers whose infants were discharged after less than one month in the NICU (because it was probable that the infants had minor problems, such as transient tachypnea of newborn [TTN] or hypoglycemia) or more than three months (in this case, the infants would probably require long-term care); 7) mothers whose infants were critically ill and/or in unstable condition; 8) mothers whose infants had multiple congenital abnormalities or had long-term problems such as gastrostomy tube (GT) placement and/or tracheotomy; 9) mothers who did not speak English or Japanese; and 10) mothers who were not willing to be interviewed.

Due to lack of enrollment in the study after six months of recruitment, the eligibility criteria were modified with input from content experts who were members of the dissertation committee. The modified inclusion criteria for mothers were as follows: 1) gave birth for the first time and underwent ART treatments/procedures to conceive; 2) gave birth to viable infants; 3) gave birth at KMCWC; 4) had infants who were admitted to the NICU; 5) had infants who stayed in the NICU at least one week after birth; 6) had infants who were in stable condition and close (within approximately a week) to being discharged to go home when the mothers consented to the study; 7) had infants who did not have congenital abnormalities; and 8) spoke English or Japanese (because the researcher is fluent in both languages).

The modified exclusion criteria for mothers were as follows: 1) underwent ART treatment/procedures to conceive but did not give birth to viable infants; 2) were multiparous; 3) did not give birth at KMCWC; 4) underwent ART treatment/procedure to conceive, but whose infants were not admitted to the NICU; 5) had infants who were discharged after less than one week in the NICU; 6) had infants who were critically ill and/or in unstable condition; 7) had infants with multiple congenital abnormalities or long-term problems such as gastrostomy tube (GT) placement and/or tracheotomy; 8) did not speak English or Japanese; and 9) were not willing to be interviewed.

Recruitment Plan

Potential participant identifications were done while the mothers' infants were receiving care in the NICU. On a weekly basis, the researcher, who was a KMCWC NICU staff nurse, reviewed the hospital's electronic medical record (EMR) system using ICD-10 Codes to identify potential participants who met the eligibility criteria for the study. When a mother meeting the eligibility criteria was identified, the researcher contacted the mother in the NICU prior to the infant's discharge from the unit to determine if she was willing to participate in the study. When the mother was willing to participate, the researcher informed the mother about the purpose of the study and the procedures that followed, including signing the informed consent document (refer to Appendix B. Consent Form), participating in an interview, and sharing demographic and perinatal information (e.g., obstetric history, gestational age when infant was born).

Setting

Participants were recruited at the KMCWC in Honolulu, Hawai`i. The KMCWC is a nonprofit hospital with 253 beds and 70 private rooms in the NICU (Hawaii Pacific

Health [HPH], "Overview" para 1, 2019). KMCWC is recognized as "Hawaii's leader in the care of women, infants and children" (Hawaii Pacific Health [HPH], "Overview" para 1, 2019) and Hawai`i's only tertiary maternal, newborn, and pediatric specialty medical center for the Pacific Basin.

Data Collection

Data collection strategies included individual, face-to-face interviews using open-ended questions. These interviews provided the researcher with mothers' individual experiences, perceptions, and coping processes during their infants' care in the NICU. In-depth interviews involving open-ended questions were "intended to elicit views and opinions from the participants" (Creswell, 2014, p. 190). According to Munhall (2012), "Interviews are most fruitful in a setting where the participant feels safe and comfortable, and when there are no interruptions" (p. 236). Therefore, the place of the interview was a private setting determined by the participant. This was also to ensure that the mother's confidentiality was maintained. The interviews were attempted to be conducted approximately two to four weeks after infants were discharged from the NICU, when infants were stable enough to be in their home environments. Specific dates, times, and locations were based on the participants' convenience. The interviews began by allowing participants to express in their own words their perceptions about being first-time mothers who underwent ART treatment and gave birth to infants requiring admission to the NICU. In addition, the researcher asked questions to clarify participants' statements, as well as used probes to obtain more detailed information (refer to Appendix D. Interview Guide).

The researcher audiotaped and transcribed the interviews. In addition, the researcher contacted the participants after the interviews in order to clarify the researcher's interpretation of what they shared during the interviews, specifically, making sure that the interpretations reflected their experiences, perceptions, and coping processes as accurately as possible (e.g., member checking).

Data Management

A study number was assigned to each participant in the study in order to maintain confidentiality. The signed informed consents, questionnaires, and audiotapes of the interviews were kept in locked files accessible only to the researcher. The questionnaires and audiotaped interview data were kept separately from the signed informed consents. The participants were not identified in any way when the research study results were disseminated (e.g., publication). Audiotapes and transcripts were destroyed after completion of the study in accordance with the UH CHS regulations.

Data Analysis

Descriptive statistics were used to analyze the demographic data. A qualitative descriptive approach was used to analyze maternal interview data to explore mothers' experiences, perceptions, and coping processes about having their infants in the NICU. According to Creswell (2014), there are specific steps to follow when analyzing qualitative data, and those were followed by the researcher. Specifically, after each interview, the researcher listened to the audiotape of the interview and wrote down any thoughts about the statements that were shared by the participant. Subsequently, the researcher transcribed the interview data. Following the transcription of the interview content, the researcher read through the entire transcript to get "a general sense of the

information and an opportunity to reflect on its overall meaning" (Creswell, 2014, p. 197). Transcripts were also read carefully, and audiotapes were reviewed again to clarify the participants' statements, as needed, and to eliminate any error that occurred during transcription.

Data analysis consisted of a systematic, iterative process of working with the interview data and reflecting about the content in order to gain an understanding of the participants' perceptions, experiences, and coping processes. This process resulted in the assigning of codes to meaningful content. Constant comparisons were done throughout the data analysis process so when new codes were identified and defined, previously analyzed interview data were reviewed to determine if the new codes also applied to those data. Similar codes were eventually grouped into broader categories. Identification of themes was the next step. Data analysis ended when no new themes emerged from the data and, therefore, saturation had been reached. Subsequently, the themes were presented in the narrative interpretation and discussion. "A final step in this data analysis involves making an interpretation in qualitative research of the findings or results" (Creswell, 2014, p. 200).

Ensuring trustworthiness of the data analysis involved a number of processes. The researcher reflected on and acknowledged the possible effect she might have had on the research process and analysis and interpretation findings (i.e., reflexivity). These reflections were documented in memos that the researcher wrote as the study proceeded in order to reduce potential researcher bias in the interpretation of findings. Memos were generated to document the process of the development of the codes, categories, and themes (i.e., audit trail). Creswell (2014) recommended to "Use *member checking* to

determine the accuracy of the qualitative findings through taking the final report or specific descriptions or themes back to participants and determining whether these participants feel that they are accurate" (p. 201). In addition, in order to strengthen the trustworthiness of the process, peer debriefings and the use of an external auditor to review the findings occurred. A UHM Department of Nursing faculty member who has experience in conducting qualitative research participated in the peer debriefing sessions and served as the external auditor. The faculty reviewed all codes, categories, and themes developed by the researcher during the process of data analysis. In addition, the faculty independently reviewed and developed codes and categories for 25% of the interviews. After each review, the faculty and researcher compared their separate analysis. In situations where there was a discrepancy between their analyses, consensus was reached and, when needed, revision of the codes, categories, and themes occurred.

Protection of Human Subjects

Mothers who were interested in participating in the study were informed about the purpose of the study and the procedures that followed if they decided to participate, including reviewing and signing an informed consent document (refer to Appendix B. Consent Form), participating in an interview, and sharing demographic and perinatal information. The researcher also answered any questions they had about the study. Mothers who agreed to participate in the study signed the consent form, and a copy was given to them. Prior to their infants' discharge from the NICU, the mothers were asked to complete the demographic data questionnaire (refer to Appendix C. Demographic Data). The researcher contacted the women after their infants were discharged from the hospital to arrange the date, time, and place for the interview. The researcher reviewed the signed

informed consent and confidentiality document (refer to Appendix B) with the mothers to make sure that they were aware of the protection of the information that they shared. The researcher also informed the participants of the use of a digital recorder, and reiterated that all of their information, research documents, and tapes would remain confidential.

A possible risk to the mothers participating in this study was a personal feeling of poor knowledge of parenting, which could have resulted in their development of feelings of inadequacy as a mother. Every effort was made so that the participants were not made to feel inadequate in their parenting based on their responses during the interviews. To protect against psychological risks, participants were told the following: 1) their participation in the study was entirely voluntary; 2) mothers were free to refuse to participate and could withdraw from the study at any time without any effect on their infants' healthcare services; 3) mothers had the right to decline to answer any questions that made them feel uncomfortable; and 4) if mothers experienced some psychological symptoms (e.g., anxiety) when answering the questions, the researcher would stop the interview and would assist the participant with obtaining an evaluation (i.e., contacting the participant's healthcare provider).

Limitations

Characteristics of the participants, such as the mothers' ages and socioeconomic status, the infants' gestational ages at birth, and the infants' conditions, could impact and/or influence the interpretation of the findings. Moreover, according to Creswell (2014), when using interviews to collect data, it is possible that "not all people are equally articulate and perceptive" (p.191). Furthermore, since the researcher was a NICU staff nurse, the researcher's presence could have resulted in biased responses from the

participants, which needed to be considered when conducting the interviews and interpreting the data.

Summary

The main purpose of this study was to investigate ART-treated first-time mothers' experiences, perceptions, and coping processes about their infants' receipt of care in the NICU. Although there were some limitations of the study, it had the potential to provide useful information to find out about this in order to identify and develop support systems and resources that could assist these mothers in coping during this stressful situation. Having more knowledge about this situation had the potential to promote the postpartum mental health of ART mothers when their infants were in the NICU, as well as facilitate mother-infant bonding.

CHAPTER 4: RESULTS

This chapter will present the results of the qualitative interview data analysis that specifically addressed this study's research questions:

1. What were the experiences and perceptions of first-time mothers who received ART treatment and who gave birth to infants who required admission to the NICU?
2. How did these mothers cope with these experiences and perceptions?

Aim/Purpose

The purpose of this study was to explore the experiences, perceptions, and coping strategies of mothers who had undergone ART and gave birth to infants who required admission to the NICU. A qualitative descriptive approach was used to investigate experiences, perceptions, and coping processes of ART first-time mothers when their infants were admitted to the NICU. The research questions were asked because of a lack of information in published literature about this issue and, in order to answer these, a qualitative approach for the research design was used. This study employed open-ended questions that were answered by participants, and an emic approach was used in order to explore and interpret meaningful themes.

Data Description

Setting

The participants were recruited and enrolled with their consent in the study at the NICU at KMCWC between August 2017 and August 2018. The KMCWC is Hawai`i's only tertiary maternal, newborn, and pediatric specialty medical center for the Pacific Basin.

Sample

Nine women meeting the modified inclusion criteria were recruited and enrolled in the study. Specifically, the modified inclusion criteria were that mothers: 1) gave birth for the first time and underwent ART treatments/procedures to conceive; 2) gave birth to viable infants; 3) gave birth at KMCWC; 4) had infants who were admitted to the NICU; 5) had infants who stayed in the NICU at least one week after birth; 6) had infants who were in stable condition and close (within approximately a week) to being discharged to go home when the mothers consented to the study; 7) had infants who did not have congenital abnormalities; and 8) spoke English or Japanese (because the researcher is fluent in both languages).

The modified exclusion criteria for mothers were as follows: 1) underwent ART treatment/procedures to conceive but did not give birth to viable infants; 2) were multiparous; 3) did not give birth at KMCWC; 4) underwent ART treatment/procedures to conceive, but had infants who were not admitted to the NICU; 5) had infants who were discharged after less than one week in the NICU; 6) had infants who were critically ill and/or in unstable condition; 7) had infants with multiple congenital abnormalities or long-term problems such as gastrostomy tube (GT) placement and/or tracheotomy; 8) did not speak English or Japanese; and 9) were not willing to be interviewed. These modifications were submitted to the IRB for review and approval, and subsequently the new inclusion and exclusion criteria were used to recruit participants. The result was an increase in the number of mothers who could be recruited and enrolled in the study.

As a result, eleven mothers signed consents to participate in this study. Of these, nine participants completed interviews. One participant (the tenth) was withdrawn by the

researcher in consultation with the dissertation chair due to difficulty in maintaining contact with her after her infant was discharged from the NICU. The eleventh mother who was recruited did not complete an interview due to the study having achieved saturation. Eight of the nine remaining participants completed face-to-face interviews, and one participant completed the study interview via telephone because the participant resided on a neighbor island (i.e., non-resident of O`ahu).

Data Collection

The initial plan was to conduct the interviews approximately two to four weeks after infants were discharged from the NICU, when infants were stable enough to be in their home environments and the mothers and families were not in the NICU environment. However, the actual interviews were conducted approximately four to twelve weeks after infants were discharged from the NICU (at 4 weeks [N=1], at 8 weeks [N=2], at 9 weeks [N=2], at 11 weeks [N=3], and at 12 weeks [N=1]). This was because the mothers were busy adjusting to taking care of their recently-NICU-graduated infants at home, and five out of nine participants had given birth to and were caring for twins. The locations of the interviews were private settings determined by the participants. Two participants preferred to have their interviews at their houses with their infants with them, two participants chose to be interviewed at their workplaces, three chose a coffee shop that was convenient for them, and one participant preferred to meet at a private KMCWC conference room. One participant completed the interview by telephone due to residing on the island of Maui. Specific dates and times were selected based on the participants' convenience. The actual time to complete the interview ranged from 30 to 75 minutes,

with the duration of the interview depending on how much the participants wanted to share (refer to Appendix D: Interview Guide).

The interviews were audio recorded. After each interview, the researcher listened to the audiotape and wrote down any thoughts about statements and perceptions that were shared by the participant. Subsequently, the researcher transcribed all of the interview data to achieve codes, categories, and meaningful themes.

Demographics. The mean age of the mothers was 37.9 years, with a range of 29 to 46 years (<30 y [N=1], 30-34 y [N=2], 35-39 y [N=3], and >40 y [N=3]). All participants were married. The majority of the participants (N=6) identified their race/ethnicity as being Asian (five of Japanese descent and one of Chinese descent), and three identified as White. None of the mothers identified as being Black, Native American/Alaskan, Native Hawaiian/Pacific Islander, or Hispanic. The participants' education information indicated that all of the mothers had graduated from high school, with the majority (N=7) having received college degrees and more than half (N=5) having completed higher levels of education (master's degrees). The majority of the mothers resided on Oahu (N=8), and one mother resided on Maui. The infants' gestational ages at birth ranged from 25 weeks to 36 weeks, with the following breakdown by gestational weeks: 22-26 weeks (N=1), 27-30 weeks (N=0), 31-34 weeks (N=7), 35-37 weeks (N=1), and >38 weeks (N=0).

This was the first pregnancy that resulted in a live birth for all of the women; however, six women had experienced a previous pregnancy loss (i.e., a miscarriage). Complications that occurred during the participants' current pregnancies included preterm labor (N=9), multiple infants (N=7 participants, with 6 of these having twin

infants and 1 having triplets), hypertension (N=3), pre-eclampsia (N=3), premature rupture of membranes (N=5), and gestational diabetes mellitus (N=1).

Data Analysis

In order to gain an understanding of the participants' perceptions and experiences, the content of the interview data was assigned codes (refer to Appendix E: Code Definitions). Constant comparisons were employed throughout the data analysis process. When new codes were identified and previous interview data were reviewed, the new codes were applied to content in those data and some codes were also modified after the review. Similar codes were grouped into broader categories. Finally, themes were determined (refer to Appendix F: Codes, Categories, and Themes). Data analyses ended when no new codes or themes emerged from the data and saturation had been reached. The description and themes are presented in the narrative discussion.

A total of 25 codes were identified, with eight categories emerging from the codes. Further analysis revealed four themes that reflected common perceptions and experiences of the participants: *Fear of uncertain outcomes, A whole new world, Gaining knowledge as a coping mechanism, and Journey to become mothers*. The analysis for each of these themes is presented in the following sections.

Fear of uncertain outcomes. Several similar words and experiences were expressed by the participants that led to the development of this theme, such as *anxious*, *scary*, *worried*, and *stressful*. These words and experiences were in response to the first interview question: "*Please share with me what it was like for you to have your baby in the neonatal intensive care nursery.*"

> I was worried. I was always worried about everything. Even though he was born safely, there was no guarantee that he would be fine. I was always worried about

> whether he would be okay and grow normally, and I was scared all that time, especially seeing the monitor. When the monitor's alarm was going off, I felt palpitations myself, and I was praying for his nurse to come to check him quickly (P8).

Another participant, who delivered the youngest infants (25-week-old twins) in this study, expressed a similar experience for a different reason:

> . . . at first it was scary because we had twins, I knew that it was probably possible they would have to be in the NICU, so I was kind of prepared for that. But I never thought I would deliver babies that early, and we didn't have a chance to see what it was like, so we were kind of nervous about that, just having all of the machines and things (P4).

The mothers' fear was due to uncertainty concerning the outcomes for their infants. "Just an everyday feeling, like it's another day that you don't know what is going to happen" (P3). This comment was made by the mother who spent the longest period (7 years) undergoing infertility treatments. Another participant, who spent a long period (5 years) doing infertility treatment, described the NICU experience stating, "It was kind of a stressful situation at first, having her be in the NICU, being uncertain about her conditions and how she was going to do" (P1).

The environment of the NICU (with equipment such as monitors and treatments such as intravenous [IV] infusions) was a source of fear for the mothers. "My babies were connected to the monitors, so I needed the nurse in order to even hold them" (P6). As first-time mothers, everything about their infants was a new experience that was taking place in an unfamiliar environment with the outcome for their infants unknown. Several mothers felt overwhelmed by the NICU environment and routines, as participant 3 described:

> Just to hold a newborn was already kind of scary because they were small and soft, but in the NICU, on top of that, the baby was connected to the monitors, and

> some were having IV fluids, lots of the lines connected to the baby. I couldn't even hold the baby properly….

Before getting pregnant, many mothers were not sure that they would ever give birth to their own child. Problems getting pregnant created more anxiety and uncertainty for the mothers when they actually conceived. "I was very surprised because I thought I couldn't be pregnant. I was relieved [when I became pregnant] but also at the same time, I was scared and worried about a miscarriage" (P5). And the anxiety and uncertainty continued throughout their pregnancy, which created a psychological burden for the mothers. Many mothers mentioned that they were worried and felt uneasy during their pregnancy because they felt something adverse might happen. A mother who delivered twins at 34 weeks of gestation made this comment:

> It was different than what I thought it would be. I think because we were trying to get pregnant for three years before we actually got pregnant. And so, for me, I thought that when we were finally pregnant, I was just going to be so happy. But I think once I got pregnant, it was so much worse because we found out they were identical twins. There are medical issues with that, and so we kept needing to go back for checkups, and then I had some bleeding. And so, I was on bedrest for a couple weeks, and so it was kind of the way I felt the whole pregnancy. I just wanted to get to 34 weeks so that they could be healthy. So, I think that was different for me because I thought once I get pregnant, I will be really happy and excited. But instead, I was just so terrified that something may happen (P6).

Many mothers also had been through complicated pregnancies, with some mothers who had been confined to bedrest for a while before delivery. Consequently, some mothers worried for the duration of their pregnancies. "I had a very difficult pregnancy, so I always had something in the back of my head that something harmful would happen. So for me I felt just more anxiety than anything" (P3). The mother who was one of the oldest participants in this study made a comment that she was initially afraid that she would lose her pregnancy, and after the birth of her infant she continued to

worry that she would lose her newborn. This concern was shared by other mothers in the study, as illustrated in the following example:

> I was always thinking the worst-case scenario because I was always scared. I was scared that I would lose him, so like I was thinking he may be dead the next day when I come back to visit him in the NICU. I was always worried about him (P8).

There were three overarching fears that the mothers expressed when reflecting about this experience: their lack of familiarity with the environment, an unfamiliar routine, and uncertainty for the infants' outcomes, both prior to and after the birth. The perception even continued after the baby was discharged from the NICU.

> I was always worried about him… even after he was discharged from the hospital, I was always worried like I was thinking again he might not be breathing the next morning when I woke up. I also bought the home monitor, which helped me to assure that he is alive. I couldn't sleep in the beginning at home after he was discharged from the NICU. I was so worried and scared unless I was constantly watching him. I just needed to see him do any movement, so when he sucked a pacifier, it reassured me he was ok. When he sleeps quietly, I try to poke his leg to see if he moves (P8).

A whole new world. The participants voiced similar experiences about the NICU in response to the interview question, *"What was the most difficult thing for you to go through during your NICU experience?*" Primarily, the NICU experiences were foreign to the mothers, since none of the mothers had visited a NICU prior to their infants' admission. For all of the mothers, the infant's condition was their main focus, and this focus directly affected their mental status. Many mothers stated that the monitors were scary for them to see and hear. The NICU environment was different compared to where infants normally transfer after delivery: the regular nursery or the mother's room. All infants admitted to the NICU are required to have monitors and other interventions, including IV insertions so there is access for therapy that needs to be administered parenterally.

> What was scary [in the NICU] was it was just monitors. Like monitors, like constantly seeing them, ah, you know, go up and down. And then, the needle, and the tests. Ah, I think in the beginning, we were not used to it, but like a lot of medical terms are thrown at us, ah, and we had to like, do learning, you know, right away. I was trying to figure out, ok, what does that mean, what does this mean. And then, yeah, like, he was on IV fluids for a while, and I guess in the beginning, like, to hold a newborn is already kind of scary because they are so soft. On top of it, he has all these wires and tubes, and you can't even like hold him properly. That was very scary (P3).

The majority of the participants knew that the infant might have to stay in the NICU after delivery; however, it was "difficult to imagine unless you have actual experience being in the NICU" (P5). From the ART treatment to becoming pregnant and having an infant who required admission to the NICU, all these experiences combined with the NICU environment were a whole new foreign world to the mothers. Especially because the standard procedure includes having the monitors, IV fluids, and tube feedings, mothers experienced fear and increased uncertainty in the NICU.

All of the nine participants expected that their infants would be born prematurely. However, two participants did not expect that their infants would need to be admitted to the NICU, while seven of the mothers did expect or prepare themselves for having their infants admitted to the NICU after the delivery. A couple of participants mentioned that they "didn't know anybody whose babies went to the NICU" (P4). "I don't know if my doctor mentioned it [the possibility of a NICU admission]. She probably mentioned it, but you really don't understand until you are in it" (P9).

Despite some sense of the possibility of the need of a NICU admission, only one of the mothers was familiar with the procedures and processes of the NICU. This was as a result of her being admitted for preterm labor and having a prenatal consultation by the neonatologists while she was being treated for preterm labor.

> I was admitted at 30 weeks, because of preterm labor. I was able to speak to, they send up one of the doctors from the NICU to talk to me, and tell me like, if your babies are born today this is what you expect. So, he went through, it was great. He told me everything like from like the incubator, jaundice, breathing, body temperature, and feeding. I think these were the five things we are going to work with them on the day they were born, like if they were born today, though, you know, you have viability at this point. So, that was really helpful for me to talk to [him], because, just having that knowledge, I like knowing rather than not knowing, just being involved with medical staff, like that was the biggest thing, like I thought like they really educated me (P7).

The majority of the mothers in the study did not have similar opportunities to familiarize themselves with the NICU and the routines and procedures that are part of the care for infants admitted to the unit. One mother who delivered twins at 34 weeks and six days gestation and was not educated about the NICU described the experience as follows:

> At first it was a surprise because we didn't expect they would be going there because they were born one day before 35 weeks. So, the doctor told us, the babies need to go to the NICU because they were born before 35 weeks. And we asked, just one day staying in the NICU? But the doctor said no, they need to make sure the babies are ok. At the beginning, we really wanted to take them home, but we were thinking it may be better for the babies to get checked. We finally accepted the recommendation. (P2)

Due to not expecting a possible NICU admission, this participant had a sense of doubt about the infants' need to be admitted for special care. In comparison, six participants expected that their babies would be admitted to the NICU even though they did not recall discussing the details about what this would involve (e.g., NICU equipment, routine, etc.). Most had been presented the possibility because they were having multiples. Having this stated as a possibility seemed to help the mothers accept the NICU admission. Participant 6, who delivered twins, described her experience as follows:

> I knew that they were going to have to go to the NICU because we had a scheduled C-section at 34 weeks, and I knew it's going to happen. And I, like especially the actual surgery itself, I didn't think I was going to hear they were

> crying and I did, and I didn't think I was going to see them and I did, and my husband was able to cut the cord, and kind of spent some time before they left, so, I think that was good. It ended up being better than what I thought it was going to be (P6).

The KMCWC NICU consists of appropriately equipped private rooms for each infant, and the majority of mothers mentioned that the private rooms were pleasant and felt more secure to them. One of the participants mentioned that one day when she was walking in the NICU to her infant's room, she noticed a picture of a butterfly, which is used as a symbol for the loss of an infant or infants in the unit. She knew the meaning because she had experienced an early pregnancy loss herself, which made her depressed too.

> The environment [having a private room in the NICU] was pleasant. And I think that makes it nicer. Because when you walk in the NICU, he has his own private room. So, you don't feel like you're looking at, you know, other babies, because I know sometimes, ah, there is another baby that is sicker, and then, you know, it feels more sad that way. Because I passed one of the hallways, and they had a butterfly (sign), and I know the, I know what it means because we had gone through it ourselves. So it's kind of like, a little bit, you know, depressing to, you know, so it's kind of nice we have our own room. Because in that room, you just focus on your baby, you don't have to look at other babies (P3).

Mothers also expressed that the private rooms created a sense that their infants were protected from being exposed to infections and being abducted.

> It's very private not being around other babies, you know…I mean that might be the concern, you know, they might be able to catch something from another baby, but they are in their own room that is secluded from other people (P1).

> They [NICU staff] were also very aware about infection control, such as washing hands before touching the babies. So, it became my routine to wash my hands at home. And, I also felt the NICU was a very secure place because of such things as ID bands, which have bar codes that are changed every day. I felt very confident leaving my babies in the NICU, feeling there was a secure place for my babies, and I didn't have to worry about abduction (P5).

However, the private room also had the potential to make the mother feel isolated and, in some situations, lonely.

> I noticed that things were really hard for me were, when my husband wasn't with me and when I was just by myself in the room with them and then I think I noticed like having the light down low, so that they, ahmm, babies could sleep. I think it was really hard for me and I turned the lights on in the room because like I just felt like I needed light, just little things, I think, were hard for me. I noticed that the days that I would like to read for a little bit or have the light turned on or call my family and do, you know, like those kinds of things made it better for me. But when I was just like in the dark room all day basically like breastfeeding them or pumping, and that was it, that was hard for me. Now, I think back, I think I was lonely, but I didn't realize how I was sad until now (P6).

Mental preparation affects the NICU experience. Participant 5, who was prepared for the possibility of her infants being admitted to the NICU before they were born, indicated that she did not have any difficulty coping with the NICU and she was very happy to have her infants at the Medical Center.

> I really feel I was happy to have babies in the NICU at KMC. I really liked the hospital. The private room was very good in the NICU. I felt comfortable and I could practice breastfeeding while I could keep my privacy (P5).

Some mothers tried to view their infants' NICU stay as a positive experience or an assurance for their infants' health condition.

> It's maybe the ideal situation that you could stay with the babies after delivery and be discharged together, but they were there because they were born as premature babies. The NICU stay and all the experiences assured me that they were okay to be discharged home. So, I felt a sense of security to bring them home. So, I think admission to the NICU is not a bad thing but creates an assurance that the baby is healthy enough to be discharged home. All the treatments and tests, like the hearing test and car seat tolerance test, also made me secure to bring them home. Overall, my NICU experiences were positive experiences (P5).

There was another view from another participant that "It was good [to be admitted to the NICU] because they were early, and they were so small, and they needed so much care, and while they were there, I could heal myself" (P9). In addition, many mothers

viewed the NICU stay as an educational period for them to learn how to take care of their infants.

> I think her being in there (NICU) educated us so much more. I think it made us feel more comfortable bringing her home, and I think that in the 7 weeks we were in there we learned how to feed her, we asked questions about how to bath her, and got used to changing her diaper (P1).

However, in general, the mothers could not imagine what exactly was going to happen to their infants or them in the NICU. The mothers were seeking reassurance that the NICU, an unfamiliar place for the mothers, was the best place for their infants at that time.

Gaining knowledge as coping mechanisms. The women were specifically asked what was the most helpful for your coping with the NICU. The participants expressed similar perceptions about what were helpful encounters and experiences that helped them cope with their infants being admitted to the NICU. The fact that everything was a new experience to the mothers in the NICU created fear regarding uncertain outcomes. All the mothers were seeking to gain knowledge in order to cope with the stressful experiences in the NICU.

> Just talking with the nurses there. Ahmm, just asking them questions whenever I needed help. Talking with the medical team assigned to us, I think just getting more information helped us cope with the situations. Being more informed, more educated, I think, was the best thing (P1).

Information, especially daily updates from the doctors and nurses, as well as being involved in the doctors' rounds, provided mothers with the assurance that they were increasing their understanding of their infants' condition, and the information was useful as a means to cope with NICU experiences. A participant stated, "It was very nice

the doctors called us every day. Daily updates about the baby were the most helpful thing to cope with NICU experiences so we knew what's going on" (P2).

Mothers were seeking knowledge not only because they "want to know everything," but also because they "want to be involved" in their infants' treatment, and their knowledge about their infants' condition and treatments helped them make decisions when options were presented to them by the NICU team. In addition, all of the participants were self-educated even before the NICU admission. They utilized social networking to get information. For example, some participants were involved in other NICU mothers' groups or had read other NICU mothers' blogs in order to prepare for their pregnancy and delivery. "I researched a lot about twins and expected them to be born as premature babies, so that's why it was easier to accept the situation" (P5). The importance of gaining knowledge during pregnancy about the possibility of a NICU admission was summarized by one of the participants when she stated,

> I think one important thing for parents in the NICU is to do some research and read about it. Get more information about the premature babies. So, that will also help you understand when the doctor explains to you why they are doing that, so you kind of know what's going on (P2).

Although the mothers tried to research the possible events that would occur during pregnancy and after the birth of their infants, their actual experiences were somewhat different than what they expected. Several mothers indicated that unexpected events such as a C-section birth or infants born much earlier than they expected resulted in increased anxiety and fear.

> My blood pressure became high, so the doctor induced me. But I didn't know about these medical interventions, which were the induction of the labor and artificial rupture of the membranes. They were unfamiliar things to me… [and during the actual delivery] I was scared. Just scared. When he was born, I thought when the baby was born, they were going to bring your baby to your side to see.

> But when he was born, many doctors came to the delivery room and took him away immediately to do some treatment. They were busy putting him on monitors, so many things (P8).

Many mothers stated, "I wanted to do everything right." Mothers were seeking information because they had a strong desire to understand about what was needed to care for their infants while in the NICU. Having such information helped them cope with the NICU environment.

> It did put us at ease after we learned what course of, I mean, it was good… doctors explained to us what course of actions they were going to take. And so, it really did put us more at ease, and we were happy that she was there in the best care" (P1).

Moreover, information from a trusted medical team was valued as a means for coping. Information was also used as a tool to help them learn how to participate in the infant's care. In addition, having consistency in the NICU routine and among the NICU team members was another way to help mothers cope with the NICU experiences; it seemed to promote rapport with the medical team.

> Pretty early on, one of the nurses became our baby's primary [NICU nurse]. So that was helpful to have, like, a person we saw, kind of consistently. So, we could ask her questions, and things, and she was, like, a familiar face. And also, we had a doctor for, like, a long period, so that was helpful too, just having the same doctor and then one more doctor, who was the one who came and explained everything to us in the beginning. So, because we saw him, you know, several times after that, I think that was helpful, just having kind of the same faces, and the same people to kind of explain things to us. It was just having a couple of people that we kind of see consistently, kind of helps (P4).

The NICU nurses were important sources of coping for the mothers. The skills, knowledge, and care that the nurses provided for the infants served to help educate the mothers about how to take care of their infants and, to some extent, prepared the mothers to take responsibility for the total care of their infants when discharged.

> I think you guys [nurses] helped a lot. Nurses were, you know, especially primary nurses, you know, very educationally consulted us, what meant, you know, how you should take care of your baby. So that was really really helpful. Because new parents, we don't know a lot of stuff: changing diapers, feeding him, how do you hold him properly, all that. I think that was really helpful. At the same time, like talking to another mom at the NICU, that was helpful (P3).

On the contrary, having different staff, especially doctors who had different opinions, made the mothers' NICU experiences more difficult.

> I think for me the hardest part was when we changed doctors because it seemed like I would build these relationships with the doctor and then it felt like the next week I would get a new doctor, and I felt like when they came to talk to me, everything that they said felt different from what the previous doctor said. Everyone has different things and they believe in and different things that they are fine to be more important, but I felt like that was really hard for me getting a different doctor with different beliefs every time. So, it was hard for me to kind of build trust with them (P6).

Mothers felt reassured that their infants were receiving the best care in the NICU because they saw that the staff were focused on their infants' needs all the time.

> I think what most helped was, we were thinking that they will be under good care there 24 hours. When we know someone there, they monitor them. That was good . . . it makes you breathe easier. We know they're under good care, monitoring everything (P2).

Another participant also noted, "after meeting with the neonatologists, getting to know the nurses there and everything, you feel comfortable, more at ease that she is in good hands" (P1). Participant 9 described, "We were very appreciative of that, there were so many nurses and so much around-the-clock care to take care of my babies, and I didn't have to worry about them."

In addition, mothers expressed the importance of their feeling cared for and supported by family members, the medical team, and other support groups such as the March of Dimes. This support helped them cope with the NICU experiences.

> I would definitely say my husband. But I am in a weird, I'm in a different situation because my husband is a psychologist. So I think because of that he really was into what I needed and what I need to hear, whereas I feel like a lot of other parents probably don't get that. But for me, he was telling me, ahmm, basically things like in order, because I was feeling very guilty leaving them [in the NICU] going home to sleep, and I was feeling guilty about not breastfeeding them all that time. So, he was really good telling me like in order to be a good mom you need to sleep sometime, and in order you to be a good mom, you need to do self-care. And I think I wouldn't be able to do that by telling myself that, but hearing it from him, it was kind of validating from my partner that, ahmm, self-care is important. I don't know how, and I kept saying, like, if I were a single mom or if I didn't have him or few or no support, I don't know how I would have done that (P1).

> I think talking about how I feel was very helpful. I had a family with me, and so, I kind of shared my feelings with them, just staying open about how I feel. And, so, that was talking to my family members and medical staff too (P7).

Journey to become mothers. All of the participants spent some time undergoing ART treatments to conceive. There were a couple of participants who indicated that they became pregnant with the first attempt of ART. Other participants waited much longer, with the longest time reported by participants in this study to be seven years. Perceptions about the ART treatments participants underwent to conceive, and the subsequent births to viable infants who were then admitted to the NICU, were very special and delicate experiences for the mothers. One mother and her partner, who spent five years doing IVF cycles, mentioned, "Infertility treatment was the hardest thing I have ever been though, ever in my life. Mentally, emotionally, physically, like it was the hardest thing I have ever been through" (P7). Participant 5 indicated the following:

> I spent two years [undergoing the infertility treatments]. When you hear "two years" you may think it's a short time, but to me, it was very long time. Actually, before the treatment started, I had wanted to have a baby for so long, for about five years. For the first year [of ART], every month I had an IUI but it wasn't successful, so then the second year we started IVF. After a second attempt of IVF cycles, I became pregnant, and I was so surprised because I thought I couldn't be pregnant [due to so many failures].

Participant 3, who spent seven years trying to get pregnant and underwent the longest period among the participants in this study to conceive, made the following comment:

> We had been trying really hard. We tried for a long time. We had been actively trying to have children for seven years. And we kept on losing them. It was not through the IVF, like, naturally. But I have gone through a lot of treatments, like, different preventative treatments or like investigative or D&C [dilation and curettage] to try to clear endometriosis. And so, we just don't know how we kept on losing them. And I also had an ectopic pregnancy. So, I was told, "There is no way you can have children on your own now because you are already older, and then, you busted one tube, and given your history of multiple miscarriages, it's very very hard to have children on your own." So, that's why we decided to go through IVF. Our friend also went through the same doctor and they had successfully had two children with him. So, we were just, like, okay, let's go ahead with it. We didn't think it was going to take the first time. We were really lucky.

Participant 9, who had spent five years trying to become pregnant, shared her experience with ART treatment and the impact on her psychological well-being:

> I think that in these kinds of treatment, it's important for the professional to realize what us, the women, are going through because it's terrible experiences. It's terrible for the relationship and terrible for your self-esteem. There is an aftermath to it. There is trauma that happens as a result of going through infertility that I have come to understand for myself because I realized after I did get pregnant, I felt insecure about being a parent. Now that I have gone through infertility, the message that you got was you are not deserving of being a parent. That's the message that gets into your head as a result of going through too much failure. It's like, almost, like the universe telling you, you shouldn't be parents. You are not equipped for it. And it's so I realized after I got pregnant, and I was like, oh my God, I am to the point like I am thinking to myself where I am scared of parenting now. I am scared that I am not going to be able to do it because I am not supposed to. I had to do own cognitive therapy on myself, because that is a result of having gone through so many years of infertility, and so I really think that the professional needs to realize is that, this is what females are going through, and what can we do to support them mentally, mental health wise, you know. Because it is mental health, after so many years, like you were going to war by yourself. It's almost like you are a war veteran by the end of it.

For some women, the ART process to become pregnant seemed like a much harder experience than having their infants being admitted to and cared for in the NICU.

> We had gone through, you know, so many tries to get her here. I think, just doing IVF, you are prepared for anything. I mean, you have so much upside down, upside down, so you can keep learning to cope better with things to... and, I think, well, that's my personal experience. We've been through so much, this was just another little bump on the road. I think, it, ahmm, and to top it off going through this whole NICU experience…. You learned to, ok, one step at a time. And we worked through. I think that was more difficult than K (baby's name) being in the NICU (P1).

Participant 6 indicated that ART treatment helped in some ways to cope with the NICU experience:

> I had been so exposed to the medical type of world, so when the babies had a blood transfusion, I wasn't freaking out about it because it was just harder in my world [referring to her ART treatment]. And when they got shots [immunization] it didn't bother me at all. I think, most moms will be really nervous, and that was just, like, I did these [hormone shots] four times a day, it makes you, so you will be okay, I think, because of being exposed to that. But I am sure, I wonder about being in the NICU, if I didn't have the treatment, if I would be probably more freaked out because I wouldn't have been so exposed to them [medical procedures] before.

On the other hand, mothers who became pregnant with the first attempt shared that the ART experience was not as traumatic as for women who had undergone several cycles of the process to become pregnant: "For us, because we got pregnant in the first treatment. So I already forgot all the pain. The hard part of IVF was the shots. It was painful" (P2). Another participant commented about how she felt lucky with the treatment because she only completed one cycle and became pregnant: "Our first IUI [intrauterine insemination], I got pregnant, so that was really fast. We were really lucky" (P4).

In general, when an infant is born, the baby stays with the mother to bond, facilitate breastfeeding, and, as much as possible, promote maternal-child attachment. However, when infants needed to be admitted to the NICU, it was a different situation for the mothers. They were required to adjust to a whole new environment and situation.

Many of them stated that they wanted to be with their infants all that time. The mothers' separation from the infants while the infants were in the NICU, including the physical distance between the mothers' residences and the NICU, influenced maternal-infant attachment. The importance of physical presence and contact with the infants after birth and during the NICU stay was stated by some of the mothers: "The most difficult part was we weren't there all that time. We felt like we were missing something because we weren't there all that time. Because they grow so fast, they will be bigger" (P2). "I wanted to do skin-to-skin right way and do all of those type of things after the delivery" (P6).

Even while physically present in the NICU, mothers felt that they were not the person responsible for their infants' daily care. Many of the typical maternal tasks that mothers plan to assume were not possible for them because of the special circumstances in which their infants needed special care. In the NICU, the primary care of the infant was provided by the NICU staff, not the parents.

> We weren't really the primary caregivers. I mean, we were there only two to three times a day, but I never spent 24 hours in the hospital with her. You come to rely on the nurses and everything to help you, so when you take the baby home, it was more nerve-wracking (P1).

Some mothers had C-section births, which made it difficult for them to visit their infants in the NICU, and some mothers had to wait more than 24 hours to see their infants. Lack of physical contact creates more fear and anxiety, which could lead to delaying maternal-infant attachment. However, physical contact with the infant reassures the mother about the well-being of her infant as well as promotes maternal-infant attachment. "When I did kangaroo care with him for the first time, I felt a little bit

relieved, and I felt he will be okay. Until that moment, I was so worried about him" (P8). Another participant who had given birth to twins mentioned,

> I think, just the normal transition to motherhood to begin with, as opposed to being in the situation where they were not coming home with me under there [the NICU], being hooked up with the wire, and it's hard. I think it was kind of hard to bond at first, then, really feel like they are mine? It's just like I felt they were babies that I loved but it wasn't like that dynamic yet because I wasn't with them all that time (P6).

This participant also stated, "Going back and forth, and just feeling guilty every time I was leaving to go home to sleep. I would feel really guilty about leaving them there" (P6). Another participant stated that the physical distance between KMCWC and her home resulted in less breastmilk production because she did not have enough time to pump her breasts due to the time spent commuting.

Breastfeeding was also a big topic for the first-time mothers. Five mothers were dealing with twins in the NICU, and it was another challenge for these mothers to be able to breastfeed both infants equally. Eight mothers desired to breastfeed exclusively. Many mothers said that lactation consultants were very helpful. However, sometimes the focus on successfully breastfeeding the infant resulted in feelings of guilt in the mother.

> I felt the pressure to breastfeed exclusively, and, like, it wasn't even the choice. Like, no one even asked me if I wanted to or not. And I mean I did but I also felt like because it wasn't a choice and I was so pushed into it—it creates a lot of feelings of guilt and doubt, especially since they are twins, I thought I would, for breastfeeding, I would have to choose one and then had to have the other one bottle-fed, so that was kind of hard for me (P6).

A final question that was asked during the interview was, "*Can you tell me what your thoughts are about participating in this study?*" All participants fulfilled their hope to become mothers, and for many, they wanted to participate in the study so it might help other women who had gone through similar situations cope with the stress of having

infants in the NICU. As illustrated in the quotes of the participants, many felt that sharing their experiences would provide support and education for other mothers.

> I guess, whatever experience that I can share with you, so you can educate other people what parents go through, I am more than willing to share my story (P1).

> I think the whole experience has gotten us, like, comfortable with what happened, like, me being more open with people. Because we know that it helped us in the beginning to have people just tell us their experiences that we just got more open, like, talking about what we have been through. I am happy to help you (P4).

> I was excited, I think, because it's important for people to be mindful of things and hear other people's experiences. And this specific situation is something that is so emotional and is, it can be really hard, so I think just knowing that you were looking more into that, I think that was really cool. So, I am happy to do it (P6).

> I have a baby now; it's a miracle to me. It's because everyone around me supported me to go through it. I was always thankful about the miracle that happened to me. So, now, I would like to support somebody who needs help. So, I am happy to help you (P8).

Summary

More most women, the desire for women to have their own children is instinctual. Women who are unable to conceive naturally often seek ART to become pregnant. Assisted reproductive technology is used worldwide to treat infertility, create new hopeful possibilities, and provide couples with the opportunity to have their own children. However, when a successful pregnancy occurs as a result of ART, pregnant women may experience several other challenges physically and psychologically as they progress through the births of their infants. Moreover, situations that require the infants to have medical care in a NICU can contribute to maternal psychological and/or physiological stress.

The experiences and perceptions of first-time mothers who underwent ART treatment and who gave birth to infants who required admission to the NICU in this study

described the fear of uncertain outcomes for their infants. The NICU experience was compared to the physical and psychological stress of their ART treatment experiences. For some, their stress about their infants' NICU admission and stay was compounded by their ART experiences, while others felt that the process of ART had prepared them for the treatments and the treatments and equipment (e.g., transfusion) used for their infants in the NICU. For all of the mothers in this study, the NICU environment and experiences of their infants were a whole new world for them. As a result, they needed and valued information from the NICU staff about the status of their infants, the various equipment used, and treatments provided for their infants. Gaining knowledge, having a set routine, seeing the same NICU staff every day, and being allowed to participate in their infants' care helped the mothers cope with this stressful experience.

Having infertility treatment is not easy; it is like a tunnel with no exit visible. All the participants went through ART treatments and became mothers as they had wished. The type and frequency of the ART treatments were individualized for each woman, and, therefore, their perceptions of the experiences varied. The experiences with ART can shape the women's experiences of stress and either help or hinder their coping if an unexpected event occurs after conceiving—especially when the event is affecting their infants. For NICU staff, knowing the perceptions of this special group of first-time mothers can inform them about how to reduce stress and provide support for these women as they transition to motherhood.

CHAPTER 5: DISCUSSION

This chapter discusses the results presented in chapter 4 about the experiences, perceptions, and coping strategies of mothers who underwent ART and gave birth to infants who required admission to the NICU. The theoretical frameworks of Mishel's (1998) *Uncertainty in Illness Theory*, Lazarus 's (1993) *Coping Theory,* and Folkman's (2010) *Stress, Coping and Hope Theory* guided the interpretation of the results of this study, leading to the identification of four themes that reflect participants' experiences and perceptions. The four themes were as follows: *Fear of uncertain outcomes; A whole new world; Gaining knowledge as coping mechanisms; and Journey to become mothers.*

Fear of Uncertain Outcomes

Uncertainty is "defined as the inability to determine the meaning of illness-related events" (Mishel, 1988, p. 225), and it is "the cognitive state created when the person cannot adequately structure or categorize an event because of the lack of sufficient cues" (Mishel, 1988, p. 225). Mishel's *Uncertainty in Illness Theory* (1988) will explain how mothers who underwent ART treatment to conceive cognitively processed their situations and how they structured to deal with their infants who required admission to the NICU for special care.

Uncertainty was a central theme for mothers who desired infertility treatment to conceive. Undergoing ART procedures itself increases perceptions of maternal uncertainty (Kim, et al., 2014), and multiple areas of uncertainty can be experienced by these mothers, such as whether or not they will be able to conceive, have a full-term pregnancy, and deliver a healthy infant. The uncertainty continued as they dealt with the new experiences and new environment related to their infants requiring admittance to the

NICU. However, the focus of uncertainty shifted from their own concerns to their infants as parental uncertainty.

Mishel (1983) explains that uncertainty occurs in situations where a person is unable to define the situation and predict the outcome. However, the focus of parental uncertainty is mainly psychological distress, which is characterized as "contribution to uncertainty (antecedents), psychological outcomes associated with uncertainty (consequences), and parents' strategies to manage uncertainty" (Stewart & Mishel, 2000, p. 300). The mothers' biggest fear was uncertain outcomes for their infants—whether the infant would survive and/or achieve normal development and growth in the NICU. This directly affected the mothers' mental health and perception of the uncertainty. For mothers with infants who were more severely ill and required more invasive treatments, their perceptions of uncertainty were greater than for mothers whose infants were not as ill. Specifically, all of the infants born to the mothers in this study were born prematurely, with some being very premature and, therefore, needing respiratory support, and some having low birth weight and requiring special care in the NICU. In addition, mothers also dealt with uncertainty regarding whether they would be able to care for multiple infants (e.g., twins) and/or care for a premature infant. Of the nine participants in this study, seven mothers delivered more than one infant, which increased their experiences of anxiety due to the possible medical consequences associated with multiple births.

As noted previously, the chance of multiple pregnancies is increased in ART procedures when more than one embryo is transferred (Ross et al., 2011). There are also many problems associated with multiple births, including an increased risk for premature delivery. Moreover, there is evidence that having undergone an ART procedure to

conceive leads to an increased risk of having an LBW infant at term and having admittance to the NICU (Wisborg et al., 2010; McDonald et al., 2009). In fact, one of the mothers in this study had an infant born at 25 weeks of gestation with a very low birth weight. As a consequence, the infant required multiple invasive interventions and stayed the longest period in the NICU.

"Uncertainty travels with psychological stress" (Folkman, 2010, p. 903). Stressful situations often involve some degree of uncertainty, including *temporal uncertainty* (when something will happen), *event uncertainty* (what will happen), *efficacy uncertainty* (what can be done), and *outcome uncertainty* (the outcome). The majority of the mothers in this study articulated additional experiences of uncertainty about their infants' short-term and long-term outcomes due to the need for specialized neonatal care while in the NICU. The unknown aspects of the NICU environment and complex treatments that some infants had to undergo increased the mothers' experiences of fear and stress regarding the well-being of their infants. Although some mothers tried to prepare mentally for possible complications that their infants might face, none of the mothers knew exactly what the NICU looked like and the multiple interventions (e.g., monitors, IV therapy, and tube feedings) that their infants needed. This compounded the expected anxiety and uncertainty most new mothers experience as they transition to their parenting role.

Perceptions of uncertainty reported by each participant were significantly different depending on the time spent undergoing infertility treatment(s) and the length of the infant's NICU stay. For a mother who had a shorter period of treatment and became pregnant after the first ART attempt and had a baby who stayed a shorter period in the

NICU, her focus was more her personal physical experiences with ART and those of her infant. Specifically, she described the hardest part of the ART treatment was the daily shots and the hardest thing in the NICU treatment was seeing her infant fed via a nasogastric (NG) tube. However, she also expressed that she felt confident taking her infant home, which was not expressed by the mothers who had undergone a longer period of infertility treatment.

Another characteristic of parental uncertainty is a feeling of insecurity about taking care of the infant (Stewart & Mishel, 2000). In the NICU, the primary care for the infant was done by the NICU staff, not by the parents. However, when the infant was discharged, the parents had to assume full responsibility for infant care and, as a result, a new sense of uncertainty would arise. "Although its intensity may diminish during periods of relative predictability, uncertainty never completely resolves" (Stewart & Mishel, 2000, p. 300). For the mothers in this study, there was some degree of ongoing uncertainty due to undergoing ART to conceive, possible complications associated with ART (e.g., multiple fetuses), the short- and long-term impact of prematurity, and their ability to successfully parent their infants once they arrived home.

A Whole New World

The NICU experience was an exposure to a whole new world for the mothers in this study. Similar to the findings of the literature, mothers stated they were not prepared at all and it was a stressful experience because often times, they "have not had the opportunity to prepare" (Howland et al., 2011, p. 91). Although some participants were told by their obstetricians that there was a possibility that their infants would be born prematurely, the consequences of a premature delivery remained relatively unknown to

them, including admission to the NICU and the subsequent treatments their infants would receive. Consequently, the mothers lacked a "cognitive map," as noted by Stewart and Mishel (2000): "Many parents have no experience and limited knowledge, that is, no 'cognitive map' with which to process these experiences" (p. 307). Some mothers were concerned about how long they would stay in the NICU and were anxious about when they could take their infants home and/or whether both twins would be able to be discharged together.

Several aspects of uncertainty have been identified, especially unknown duration of the situations or conditions that could result in adverse outcomes. This perpetuates the stress that mothers/parents experience when their infants/children are hospitalized (Stewart & Mishel, 2000). The results of this study did find that the length of the infants' NICU stay affected the mothers' psychological status. This was because the length of the NICU stay applied not only to the infants' conditions and having to undergo invasive treatment, but also to the mother's routines. The longer the infant stayed in the NICU, the more the mother had to develop and adapt her own routine to accommodate the new environment in the NICU (e.g., NICU routines, noise, etc.). Mothers had to create some type of comfortable environment where they were not allowed to fully take care of their infants and, therefore, they relied on the NICU staff to meet most of their infants' needs. These factors seemed to influence maternal confidence in regard to assuming responsibility for the care of their infants when they were discharged. Specifically, some mothers whose infants had a shorter NICU stay expressed that they were eager to take their infants home and become a family unit. On the other hand, mothers whose infants spent a couple of months in the NICU expressed anxiety when they heard their infants

would soon be discharged because they had relied for a longer period of time on the NICU staff to care for their infants' complex needs. There was a realization that they would be responsible 24 hours a day, 7 days a week in their home environment without the NICU nurses to turn to for guidance. The perceptions of the uncertainty due to the NICU admission and stay were transformed to a new uncertainty at home as they transitioned to the primary caretakers of their infants.

"During the initial phases of a child's illness, parents are confronted with considerable novelty and confusion not only about their child's condition, but also about the health care environments in which they find themselves" (Stewart & Mishel, 2000, p. 307). The environment influenced the mother's psychological and physical status. When an infant is admitted to the NICU, he or she is required to be connected to monitors and receive IV therapy as part of the standard procedures in the unit. Having monitors allows the NICU staff to observe and assess the infant's condition and to use it as a tool to make decisions for interventions. These are necessary tools that are common in the NICU; however, for the mothers in this study these appeared to contribute to more maternal perceptions of fear of uncertainty as a result of the mothers having to adjust to a new unfamiliar environment.

As many mothers mentioned, having primary care nurses was very helpful in terms of coping within the NICU environment. Interactions with the medical team, especially the infants' primary nurses, resulted in the mothers feeling supported and experiencing a lower level of maternal uncertainty (Steward & Mishel, 2000). Having a good rapport with the nurses and trusting them with the care of their infants was noted by the mothers to help them feel comfortable when the mothers left the NICU for any period

of time. In particular, mothers noted that just having physical distance from the infants created anxiety for the mothers because they were not able to view their infants constantly, as in a home environment. Therefore, when mothers were not able to stay with their infants (i.e., having to return to work), the frequent daily updates about their infants' status from doctors and nurses created the sense that someone was closely watching their infants, and this perception eased the mothers' anxiety. The mothers noted that they were always seeking information to fill the gap caused by their physical distance from their infants in order to understand their health status.

Gaining Knowledge as Coping Mechanisms

According to Mishel (1988), perceptions of uncertainty will increase when there is ambiguity and/or a lack of familiarity regarding the event(s), lack of information about the situation, and unpredictability in regard to the treatment outcome and/or prognosis. Coping is a key concept for adaptation to a stressful situation and/or transitioning to a new role (Lazarus, 1993). When people are experiencing internal and/or external stressful events they have to overcome, *coping* (a person's thoughts and behavior) will occur (Folkman, 2010). To determine what might have facilitated the mothers' coping with their infants' NICU admission and stay, they were asked the following interview questions: *"What were the ways that you coped with having your baby in the intensive care nursery? What helped you the most to cope?"* It was clear from the mothers' responses that obtaining information and gaining knowledge about their infants' status, as well as the plans for the infants, were key in the mothers' ability to cope with their infants' NICU stay. Most mothers emphasized that the information provided by the NICU team made them feel more at ease because they understood what exactly was

happening to and what they could do for their infants. When a person who is experiencing uncertainty, anxiety, and stress can identify, develop, and use coping strategies successfully, then adaptation will occur (Mishel, 1988). The knowledge mothers gained appeared to be a useful tool to cope with their uncertainty and stress and, for some, it provided a means for them to adapt to the unfamiliar situation that they were experiencing. For example, some mothers indicated that being in the NICU provided them with important positive experiences that helped them learn about and develop skills in taking care of their infants.

"Education is proposed to have both an indirect and direct relationship to uncertainty" (Mishel, 1988, p. 227). Education provided the mothers with enhanced knowledge and meaningful context. Providing appropriate parental education, including knowledge of a premature baby's behaviors, and access to parenthood and psychological resources to support them may decrease the incidence of depression and anxiety disorders (Melnyk & Feinstein, 2009). Teaching the mothers about the recommended NICU treatments for their infants and explaining to them what they can expect in the NICU (e.g., routines, equipment used, etc.) are important for the mothers' peace of mind. This education, along with encouraging them to participate in their infants' care as appropriate, can facilitate their confidence in infant caretaking after discharge from the hospital. Hands-on teaching can promote maternal-infant attachment and assist with maternal adaptation to the new NICU environment.

According to Folkman (2010), the use of the Internet is a major source that is often used to get "other" opinions and serves to help some individuals cope when encountering a stressful and/or uncertain situation. All the participants in this study first attempted to

seek information through social networking services (SNS) to find answers to their questions and educate themselves prior to when their infants were admitted to the NICU. Overall, the participants were well educated, with five out of nine having completed graduate-level education. They appeared to be capable information seekers who used a number of resources available to enhance their knowledge about the stressful situation that they were facing. The process of seeking and obtaining information on their own appeared to be a coping mechanism they used to clarify and confirm, or in some instances possibly contradict, information they may have been receiving from health professionals and anecdotal information from their family members and friends.

Consistency in the NICU environment and routine was another factor that the mothers cited was helpful for them to cope. When mothers saw the same NICU staff involved with their infants' care, they felt much more comfortable, especially having primary nurses for their infants from the NICU admission though their infants' stay in the unit. They felt that establishing a good relationship with the NICU team was important to help them cope, because they felt that they could trust those most familiar to them to provide optimal care for their infants. Finally, participants indicated that feeling cared for by the NICU team facilitated their coping with and adaptation to the new environment.

Journey to Become Mothers

Infertility is a central concern in a woman's life and undergoing ART treatment not only is physically intense and stressful, but also, more significantly, affects individuals' psychological transformations (Malina & Pooley, 2017). Many mothers reported that undergoing ART treatment was the hardest event in their life, especially when they were dealing with prolonged uncertainty.

For people who are coping with uncertainty and under serious and prolonged psychological stress, hope is a key element in adaptation to the event that stimulated the uncertainty (Folkman, 2010). In this study, mothers who had undergone ART clung to the *hope* that they could become pregnant and be mothers. Subsequently, when they became mothers, but their infants required admission to the NICU, they were again filled with uncertainty specifically focused on their infants, which affected their psychological, physical, and, for some, spiritual wellbeing.

The participants in this study used ART treatments to conceive as a last resort. The majority had been through many ART treatment cycle failures. As a result, there was a perception of not expecting too much from the ART treatment cycle in order to avoid the disappointment that could occur when a pregnancy either did not happen or ended in a miscarriage. This was a way to cope with the uncertainty of the current ART treatment cycle outcome and protect them from more psychological distress. Information shared by the participants in the study about how they coped during their infants' NICU stay revealed that the mothers' previous approach to coping with their ART due the possibility of an unsuccessful ART treatment outcome was used subsequently after their infants' births. Specifically, some mothers indicated that they felt that they were prepared for a "worst-case scenario" situation when their infants were admitted to and during the stay in the NICU. This was a result of the stress, uncertainty, and coping that they experienced during their ART treatments. Since this approach had worked to buffer their anxiety, uncertainty, and distress during their infertility treatments, they applied it to this new stressful and uncertain situation about their infants' outcomes.

Moreover, going through the ART process impacted the mothers' psychological status while their infants were in the NICU, either by helping to improve the psychological status or making it worse. One of the participants mentioned that exposure to ART prepared her for the process of her infant's treatments. She felt that her infant's NICU stay and treatments were not anxiety-provoking because she had gone through so much in order to get pregnant. It appeared that the coping mechanisms that she had used as she worked through the psychological experiences of undergoing ART were used by her to decrease her perceptions of anxiety and uncertainty during her infant's NICU stay. Another mother reflected on how she had felt when she had had to have injections every day to conceive. As a result of that experience, she seemed to feel more upset when observing her infant undergo similar procedures—it was a psychological booster that exacerbated her feelings of distress.

The duration of infertility treatment appeared to impact some mothers' psychological status. One of the participants who successfully conceived after her first ART treatment indicated she had already forgotten the pain associated with the multiple daily injections that were required as part of that treatment. In comparison, a participant who spent a longer period undergoing ART treatment stated that the ART process was the hardest time in her life, and she viewed it as being much harder than having her infant admitted to the NICU. However, in some ways, the ART treatments that the participants underwent seemed to help them cope with the NICU experience. The use of technology and administration of medication (i.e., hormones) via daily injections without the absolute guarantee of successful achievement of conception seemed to be a process

preparing them for the unknown outcome of their pregnancies and, once their infants were admitted to the NICU, the well-being of their infants.

According to Folkman's stress, coping, and hope theory (2010), stress is defined as a contextual process that arises between an individual and an environmental situation, and it will change over time. Stress is a personal perception that indicates that the person is overwhelmed using their typical coping processes. Many participants described that having ART treatment was the hardest thing that they had had to endure in their life, a horrible experience. Some commented that going through ART and coping with the stress associated with it was much harder than having an infant in the NICU. Some noted that they felt depressed after each failed ART treatment, but very few mentioned a sense of depression during their infants' NICU stay. It could be that having achieved a pregnancy and giving birth after the challenges they had faced with ART and its uncertain outcomes provided them with a sense of hope about their infants' outcomes, which helped them cope during another stressful period in their lives.

"Mothers of infants with special care needs also need special care themselves" (Korukcu, Deliktas, & Kululu, 2017, p. 594). For all of the mothers, their infants' NICU admission created a physical distance between them and their infants, although this period of separation varied among the mothers. Maternal-infant separations can affect maternal attachment to offspring and their transition to becoming a parent (Jones & Santamaria, 2018). In most circumstances, when an infant is born the infant stays with the mother, unless there is an urgent maternal or infant complication that has to be addressed. Even in some of these situations, maternal contact with the infant is allowed, albeit briefly. Infants remaining with their mothers after birth facilitates skin-to-skin

contact and maternal-infant attachment, and allows immediate breastfeeding (Moore, Anderson, Bergman, & Medley, 2016). Delivering a premature infant is extremely stressful for parents (Brett et al., 2011), and separation from the infant due to the need for a NICU admission can contribute to significant issues for a woman in terms of her adaptation to the new role of motherhood (Heydarpour, Keshavarz & Bakhtiari, 2017). All of the participants in this study gave birth to premature infants and, consequently, were separated from their infants after birth due to the need for admission to the NICU. Several of the participants expressed feelings of anxiety, uncertainty, guilt, and anguish about leaving their infants alone in the unknown environment of the NICU. However, once the mothers could physically see and visit their infants as well as gain knowledge about the NICU and staff, it provided them with a sense that their infants were being well cared for, and their anxiety and stress were decreased.

"A positive outcome of uncertainty which some parents describe is the adoption of a new outlook on life" (Stewart & Mishel, 2000, p. 309), and continuously perceiving uncertainties will "promote a new, more probabilistic approach to finding meaning in life" (Stewart & Mishel, 2000, p. 309). One mother described "taking it one step at a time" during her infant's NICU experience, and this was a coping approach she used during her ART experience. This coping process has been described by Stewart & Mishel (2000) in reference to continuous perceptions of uncertainty that promotes a new worldview in some parents of vulnerable children, with the parents' coping by maintaining the philosophical thought of "taking it one day at a time" (p. 309). This approach can facilitate successful coping strategies and can result in the personal growth of the individual facing challenging situations that are stressful and uncertain (Stewart &

Mishel, 2000, p. 309). All of the participants in this study shared perceptions and experiences about their individual personal journeys during their infants' NICU stays that reflected various coping strategies to deal with stress and uncertainty during this time in order to successfully transition to motherhood.

Strengths of the Study

This was the first study that was designed and conducted to address the perceptions and experiences of mothers who had undergone successful ART treatment and a pregnancy and, subsequently, had their infants admitted to the NICU. All of the mothers in this study were well educated, came from socioeconomically stable situations, were married and had spouses actively engaged in their infants' care, and had insurance coverage for their care. The participants had demographically varied backgrounds; however, although this study took place in Hawaii, none of the participants indicated that they were Native Hawaiian or part Native Hawaiian. Most of the participants described themselves as "locals" (generations of their families had been living in Hawaii); however, a couple of the participants were from the mainland and Canada. In addition, women recently coming to Hawaii from Japan were included in the study, since the researcher is from Japan and is fluent in the language.

Limitations of the Study

This research involved a small sample, and it was a very selective group of women utilizing services at a hospital in Hawai`i that specialized in maternal-child care. The participants in the study had undergone only two forms of ART (i.e., IVF and IUI); none of the participants had other types of ART procedures. This study did not include the partners of the participants and, therefore, did not include the partners' experiences

and perceptions about this issue, nor an exploration of the impact on the relationships and the interactions between the partners and participants and how that affected the mothers' coping.

The timing of the interviews in this study could also be viewed as a limitation because they took place several weeks to months after the actual experiences of being in the NICU environment, as well as having a final cycle of ART to conceive. This could have resulted in recall bias on the part of the mothers about several aspects of their NICU experiences.

Mishel's uncertainty theory indicated that perception of uncertainty is influenced by cultural difference. This study particularly applies to Western society; thus, it needs to take into consideration that women from other cultures may have different outcomes. For example, studies conducted in more heterogeneous populations in different settings and/or cultures may reveal different findings.

In addition, the researcher was a NICU nurse at KMCWC and all the participants were aware of this fact. This could be an advantage regarding recruitment of participants for the study; however, there is the potential for bias on the part of the researcher's interpretation of the data collected.

Conclusions

Having an infant admitted to the NICU after undergoing ART treatment(s) to conceive was acknowledged as a very stressful experience for the participants in this study. Considering the impact of such experiences and perceptions on maternal postpartum mental health, interventions that could assist with successful coping should be made readily available to this group of new mothers. Many of these interventions exist,

including appropriate education for mothers that is specific to their particular circumstances (i.e., individual education), group education (e.g., NICU tours and information about NICU routines), consultation with a mental health provider when significant distress is being experienced by the mother, and information about community resources such as the March of Dimes. The findings of the study also indicated that there was a lack of social support groups available for this particular group of mothers, which is something that can be developed in collaboration with other agencies (e.g., March of Dimes).

The interviews of the participants in this study provided some new information about these mothers' unique experiences and perceptions, but some of the findings were similar to the experiences of non-ART mothers whose infants had NICU stays. Specifically, themes that were common to both groups included maternal uncertainty, anxiety, and need for knowledge about their infants' well-being while in the NICU. The difference between the groups was that many of the mothers who had undergone ART noted that this was a really traumatic experience, and, for a few, having an infant in the NICU was a less traumatic experience because the ART treatment had created more intense feelings of distress. For some of the mothers in this study, the exposure to and coping with the stress of the technology and procedures (e.g., injections) that were a part of their ART treatments helped their adjustment to having their infants in the NICU. However, for other mothers in this group, watching their infants experience injections and invasive procedures, or have routine equipment used to assess their well-being (e.g., monitors), was more uncomfortable and upsetting due to their ART experiences.

This study indicates some new findings specifically in regard to mothers who required ART treatment and had a viable birth but whose infants needed special care in the NICU. Their experiences of stress and ways of coping focused on adapting to a new, unfamiliar environment while transitioning to motherhood.

Recommendations

A couple of decades have passed since ART was established and the prevalence of the utilization of ART treatment to achieve conception has increased and become more complex. In addition, the perinatal consequences of employing ART to successfully conceive has increased, with one of the most important consequences being premature births. As a result, an increasing number of women who have successfully conceived after undergoing ART will give birth to preterm infants and these infants will, in all likelihood, require admission to and some length of stay in a NICU for special care after birth. Therefore, gaining insights into this group of mothers' perceptions about their NICU experiences in terms of stress and coping strategies is important. To date, this study is the only one that has focused on this group of mothers to explore these issues. Therefore, more research is needed to determine what interventions may best assist mothers in this group transition to parenthood while dealing with the stress of having their infants in the NICU.

Most women undergoing ART to conceive have partners and, therefore, it is important to consider the couple as a unit when exploring stressful situations that can affect their relationship and their transition to parenthood. These experiences may be similar or different for couples that have successfully achieved pregnancy via ART but subsequently have their infants needing NICU care. Therefore, expanding the research to

address the perceptions and coping strategies of both partners should be studied systematically in future research in order to ensure the successful transition to parenthood while coping with an infant in the NICU. For example, the mother's partner might be worried for both mother and infant, while the mother might be focusing on only the infant.

Moreover, when an infant is admitted to the NICU, most of the time, the partner is the one to accompany the infant, while the mother recovers from the birth. Thus, the partner is the first person to observe the infant in the NICU with all the interventions that initially take place, which may increase experiences of stress in the partner. In addition, it is often the partner who provides the mother with details about how the infant looked and how well s/he is doing in the NICU from the partner's perspective. This responsibility could be overwhelming for the partner to deal with unless additional support is available to meet the partner's needs.

Research focusing on mothers of other ethnic backgrounds, cultures, religions, geographic areas, and types of ART that they underwent to achieve pregnancy should be investigated. This is important because cultural perceptions toward having ART treatment to conceive and give birth to a child may have different implications.

This study included first-time mothers only. Undergoing ART treatments to conceive after successfully having previous pregnancies and having children may have additional challenges and perceptions because those mothers need to take into consideration the children that they have left at home while focusing on the care of their infant in the NICU. This could possibly affect the mothers' psychological status and coping, as well as different types of family dynamics.

Implications for Future Research

The use of ART procedures and their success rates have increased. This is as a result of the increasing percentage of infertile couples that are being observed (Malina & Pooley, 2017). Subsequently, it could be surmised that the use of ART is also increasing. The use of ART is associated with an increased incidence of perinatal complications including multiple births, prematurity, low birth weight (LBW), infant deaths, elevated risks for birth defects, and infant disabilities (Sunderam et al., 2015). Ultimately, with the advance of NICU technology, the survival of high-risk preterm and critically ill infants who need treatment in the NICU is expanding. Therefore, replicating this study with a larger sample would provide an opportunity to confirm the results of this initial study and determine more details about this problem in order to develop and implement strategies to improve maternal coping and facilitate transition to parenthood for this special group of mothers and couples.

Lastly, something this study did not investigate was the association between the duration of the infant's stay in the NICU and maternal psychological stress over time. It included only one point in time to reflect on the mothers' total experiences in the NICU after they were home with their babies. It is possible that mothers were much more anxious when they recalled their experiences because they were out of the system and at home, with the full responsibility of taking care of their infants. The participants could have recalled their NICU experiences differently due to the passage of time and distancing from the event. In addition, this study did not include any quantitative tools to measure maternal distress, uncertainty, and depressive symptoms. Future studies should

consider a triangulation design that could provide more comprehensive appreciation of the complexities of the mother's experiences.

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Appendix A

Literature Review Matrix

International Studies

Authors, Year, Title Country	**Purpose of Study**	**Key words**	**Methods/ Design/ Sample**	**Measure/ Intervention**	**Concept/ Findings**	**Comments**
McMahon, Ungerer, Tennant, & Saunders. 1997. Psychosocial adjustment and the quality of the mother-child relationship at four months postpartum after conception by in vitro fertilization. Australia	To examine psychological adjustment to early motherhood at 4 months postpartum in mothers who conceived by IVF.	Psychological, adjustment, parenthood, mother-child relationship, IVF-ET	Controlled clinical study. N = 127 primiparous women; 65 women undergoing IVF & 62 age-matched women with no history of infertility.	Completion of questionnaires, interviews, videotaped interaction.	IVF, parenthood. Mothers who conceived by IVF did not differ from control mothers on measures of anxiety, PPD, marital satisfaction.	IVF + motherhood
Repokari, Punamaki, Poikkeus, Vilska, Unkila-Kallio, Sinkkonen, Almqvist, Tiitinen, & Tulppala. 2005. The impact of successful assisted reproduction treatment on female and male mental health during transition to parenthood: a	To reveal whether there are differences in mental health during the transition to parenthood between parents undergoing treatment with ART and those who conceive spontaneously.	ART, infertility, mental health, social and child-related stress.	Prospective controlled longitudinal study. N = 746 (367 ART couples with singleton pregnancy and 379 control group couples with spontaneous singleton pregnancy).	Men and women separately filled in questionnaires at the 18^{th}-20^{th} week of pregnancy, 2 months postpartum and 1 year postpartum.	ART, parenthood/ ART women had fewer depressive symptoms during pregnancy than controls, but at 1 year their depressive symptoms were at same level as seen in control. ART men reported generally fewer mental changes among controls, whereas no impact on ART couples.	ART + parenthood

prospective controlled study. Finland						
Fisher, Hammaeberg, & Baker. 2005. Assisted conception is a risk factor for postnatal mood disturbance and early parenting difficulties. Australia	To investigate whether assisted conception is associated with an increased risk of admission to a residential early parenting program for treatment mood disorder or infant feeding or sleeping disorders in the postpartum year.	ART conception, postpartum depression, parenting difficulties.	Systematic audit of 745 consecutive medical records from a private hospital mother – baby unit.	Edinburgh Postnatal Depression Scale (EPDS) score.	ART, parenthood/ Assisted conception significantly increased rate of early parenting difficulties.	ART+ parenting. Audit only, no intervention.
Cox, Glazebrook, Sheard, Ndukwe, & Oates, M. 2006. Maternal self-esteem after successful treatment for infertility. United Kingdom	To investigate self-esteem during pregnancy after previous infertility and establish the relationship among self-esteem, anxiety during pregnancy, and parenting self-efficacy.	Self-esteem, Anxiety, parenting self-efficacy, IVF.	Controlled longitudinal study. N = 128; 51 in the study group; 77 in the control group.	Self-esteem and anxiety were measured by postal questionnaire at two points during pregnancy (18 weeks and 28 weeks) and interviewed at 6 weeks postpartum. Measures of parenting self-efficacy and anxiety were taken at the time of interview.	ART/ There were no significant differences between the IVF group and the control group in terms of anxiety during pregnancy and in the postpartum period and in terms of parenting self-efficacy postpartum.	ART+ Mental health
Harf-Kashdaei, & Kaitz 2007. Antenatal moods regarding self, baby,	To evaluate the antenatal feelings of women who conceived by IVF, with a focus on	Affect, mood, IVF, Pregnancy.	Controlled, prospective study. N = 60 women; 30 women who conceived by IVF	Validated interview and standardized questionnaires.	ART/ IVF group scored lower on negative affect and higher on measures of (positive) mood	ART + mental health Mood regarding spouse depended

and spouse among women who conceived by in vitro fertilization. Israel	their moods regarding self, baby, and spouse.		and 30 demographically matched women who conceived naturally.	The interview (42 questions) focused on three content areas: self, baby, and spouse.	regarding self, baby, and spouse. No differences between groups were found on measures of positive affect, depression, or anxiety. Women with more IVF cycles (2-3) had lower negative affect scores than women who had conceived after the first treatment cycle	on whether or not he had been the sole source of the couple's infertility.
Fisher, Hammaeberg, & Baker. 2008. Antenatal mood and fetal attachment after assisted conception. Australia.	To identify prevalence and determinants of antenatal mood disturbance and other risks for early parenting difficulties after assisted conception.	Infertility, antenatal anxiety, antenatal attachment, antenatal depression, ART.	Prospective longitudinal investigation. N = 183 women.	95% of whom completed both early and late pregnancy assessments.	ART/ There were low rates of antenatal mood disturbance and other risk factors for PPD. Pregnancy and motherhood might be idealized after ART, and preparation for the realities of infant care might then be insufficient.	ART + mental health Australian's Medicare is a universal healthcare. Unlimited number of ART treatments available.
Hammarberg, Fisher, & Wynter. 2008. Psychological and social aspects of pregnancy, childbirth and early parenting after assisted conception: a systematic review. Australia	To review the available evidence of the psychological and social consequences of pregnancy, childbirth, and early parenting after assisted conception systematically.	Pregnancy, ART, psychology.	N = 28 studies as a result of a systematic search for English-language research articles on psychological and social aspects of pregnancy, childbirth, and the first post-partum	Reviewed 28 studies, which met inclusion criteria.	ART, parenthood/ Marital satisfaction, emotional well-being and self-regard in pregnancy, attachment to the fetus and parents-infant relationship in ART group are similar to comparison group. Anxiety about the survival of the fetus and early parenting	ART + parenting. Methodological differences may explain the lack of consistency in finding of the influence of infertility and ART on some aspects of the transition to parenthood.

			year after ART conception.		difficulties appear to be higher and post-natal self- confidence lower.	
Monti, Agostini, Fagandini, Paterlini, Battista La Sala, & Blichstein. 2008. Anxiety symptoms during late pregnancy and early parenthood following assisted reproductive technology. Italy.	To evaluate the relationship between ART and anxiety symptoms during late pregnancy and early parenthood.	Anxiety, ART, IVF, post-partum depression, psychology.	Longitudinal prospective study. N=87 subjects with 48 ART (25 mothers and 23 fathers) and 39 non-ART mothers (only mothers, no fathers were included for non-ART group). Study compared between women with ART and women with non-ART, and between ART women and ART men.	ASQ-IPAT Anxiety Scale and EPDS at 30-32 weeks of gestation, and at one week and three months after delivery.	ART/ ART women showed higher scores for latent anxiety than non-ART women at 3 months after birth and showed no difference from ART men in all assessments.	ART+ PPD Higher anxiety in ART pregnancy-birth process. Included ART men. Limitation: relatively small sample. Cultural difference needs to address.
McDonald, Han, Mulla, Murphy, Beyene, & Ohlsson. 2009. Preterm birth and low birth weight among in vitro fertilization singletons: a systematic review and meta-analyses. Canada	To determine the risks of preterm birth (PTB) and low birth weight (LBW) in singletons conceived through IVF/ intracytoplasmic sperm injection (ICSI) compared to spontaneously conceived singletons.	IVF, preterm birth, low birth weight, singletons.	A systematic review and meta-analyses. Medline and EMBASE were searched using comprehensive search strategies. 17 studies were used for this meta-analysis.	The MOOSE guidelines for meta-analysis of observational studies were followed.	ART/ IVF singletons have significantly increased risks of PTB, LBW and other adverse perinatal outcomes compared to spontaneously conceived singletons after matching or controlling for maternal age at least.	ART + preterm birth

Monti, Agostini, Fagandini, Paterlini, Battista La Sala, & Blichstein. 2009. Depressive symptoms during late pregnancy and early parenthood following assisted reproductive technology. Italy.	To evaluate the relationship between ART and depressive symptoms during late pregnancy and early parenthood.	IVF, ART, depression, psychology.	Case-control longitudinal study. N=87 subjects; 48 ART patients (25 mothers, 23 fathers) and 39 non-ART mothers were evaluated.	Evaluated by the ASQ-IPAT Anxiety Scale and EPDS at 30-32 weeks of gestation, and at 1 week and 3 months after delivery.	ART, Parenthood/ EPDS scores were higher in ART women compared with non-ART women during all assessments and higher during the third trimester of pregnancy and at 1 week postpartum compared with ART men. The prevalence of depressed subject was significantly higher in ART women compared with non-ART women during the antenatal assessment.	ART + mental health + parenthood. ART pregnancy is more frequently associated with depressive symptoms that may persist after delivery. Need monitor ART pregnancy.
Hansen, Colvin, Petterson, Kurinczuk, Klerk, & Bower. 2009. Twins born following assisted reproductive technology: perinatal outcome and admission to hospital. Australia.	To investigate the rate of hospital admission by 3 years of age in twins born following ART compared with their spontaneously conceived.	ART, hospital admission, IVF, morbidity, twins.	Cohort study Chart review N =700 children who were born as twins with ART and 4097 children through spontaneous pregnancy. Investigated perinatal outcome and hospital admission (including NICU admissions) during the first 3 years of life for all twin children born in	The data analysis was done with SPSS and SAS/STAT.	ART/ ART twins had a greater risk of adverse perinatal outcome, including preterm birth, low birth weight, and death compared with non-ART twins. ART twins had a longer birth admission and higher risk of hospital admission. The increased risk of hospital admission continued in the second and third year but was not statistically	ART + Twin The cost of an ART twin delivery + extra ~4 days on average spent in hospital at birth, x4 increased risk of admission to a NICU and the ^ risk of hospital admission in the 1-3 years of life. Need to consider: • Extra cost of ART twin deliveries

			western Australia between 1994-2000.		significant in the third year.	• Benefit of elective single embryo transfers (SET). UK: "multiple births minimization strategy". Belgian: 6x reimbursement.
Schmidt. 2009. Social and psychological consequences of infertility and assisted reproduction - what are the research priorities? Denmark	To increase awareness about the social and psychological consequences of infertility and assisted reproduction and to highlight gaps in knowledge.	Assisted reproduction, communication, coping, infertility, psychology, social support.	The article is a commentary, not a study, that focuses on research on the social and psychological consequences of infertility and its treatment based on the author's knowledge of this field over the past 15 years.	Retrospective literature reviews.	Infertility, ART/ There is a lack of studies investigating the impact of infertility and its treatment on social relations and of studies which have used the couple as the unit of analysis. More large-scale, long-term prospective cohort studies which address the social as well as psychological consequences of infertility are needed.	ART+ mental health
Vilska, Unkila-Kallio, Punamaki, Poikkeus, Repokari, Sinkkonen, Tiitinen, & Tulppala. 2009. Mental health of mothers and fathers of	To evaluate the psychological well-being of ART parents and non-ART parents. To investigate the impact of parity,	ART, twins, depression, anxiety, prematurity.	A prospective longitudinal questionnaire study. 458 ART couples (91 pairs of twins and 367 singletons) and 399 control	Symptoms of depression and anxiety, sleeping difficulties, and social dysfunction were addressed via a questionnaire.	ART, parenthood/ Twin parenthood, but not ART, has a negative impact on the mental health of mothers and fathers during the	ART + Twin + transition to parenthood. Prematurity didn't differently affect maternal

twins conceived via assisted reproduction treatment: a 1-year prospective study. Finland	prematurity, and children's health-related factors on mental health status at birth, at 2 months, and 1 year old.		couples (20 pairs of twins and 379 singletons).	General Health Questionnaire (GHQ-36) was used @ 2nd trimester (18-20 weeks), when the children were at 2 months old, and at 1 year old. Mothers and fathers were asked to fill out the questionnaires separately.	transition to parenthood. ART parents' mental health was not affected by parity or children's health-related factors.	mental health, but it had a negative impact on control father's social dysfunction.
Akyuz, Seven, Devran, & Demiralp. 2010. Infertility history. Is it a risk factor for postpartum depression in Turkish women? Turkey	To assess postpartum depressive symptoms in women who had been successfully treated for primary infertility at 2 teaching hospitals in Turkey.	ART, infertility, PPD.	Cohort study. N = 157; 51 fertile compared to 105 infertile women.	Descriptive Information Questionnaire developed by authors, and adopted Beck Depression Inventory, and adopted Postpartum Depression Scanning Scale.	ART/ A history of infertility is not a major factor in PPD, but history of depression may contribute to its development during pregnancy and in the postpartum period.	ART + mental health. Limitations of the study (findings can't be generalized); the women in this study came from unique groups and had a higher than average level of education and socioeconomic status. They also had singleton pregnancies only and gave birth to infants with no psychological or physical disabilities.

Gameiro, Moura-Ramos, Canavarro & Soares. 2010. Psychosocial adjustment during the transition to parenthood of Portuguese couples who conceived spontaneously or through assisted reproductive technologies. Portugal	To describe the psychosocial adjustment during the transition to parenthood of Portuguese couples who conceived via ART in comparison to couples conceiving spontaneously.	ART, infertility, Portugal, men, women, parents, transition to parenthood.	Longitudinal prospective study N = 66; study group included 35 couples who conceived through ART; control group included 31 couples with a spontaneous conception (SC).	Couples completed self-report questionnaires regarding their perceptions of pregnancy and parenthood, psychological distress, quality of life, marital relationship, and parenting stress.	ART, parenthood/ Portuguese men and women who conceived through ART showed psychosocial adjustment levels during the transition to parenthood similar to men and women who conceived spontaneously.	ART + mental health. Women have and benefit more from diverse sources of social support and that friendship relations remain important extra familial connections for new mothers.
Wisborg, Ingerslev, & Henriksen. 2010. In vitro fertilization and preterm delivery, low birth weight, and admission to the neonatal intensive care unit: a prospective follow-up study. Denmark	To compare the risk of preterm delivery, low birth weight, and admission of the NCIU in women pregnant after fertility treatment and subfertility women with the risk in fertile women.	ART, epidemiology, infertility, IVF/ICSI outcome.	Prospective follow-up study. N=20,080 live born singletons. Infertility treatment group and non-IVF group. Limited to singleton and primiparous.	Two questionnaires were sent to the participants during pregnancy. Data were statistically analyzed.	ART, Infertility/ A statistically significantly increased risk of preterm delivery and very preterm delivery in women who conceived after IVF compared with fertile women. The risk of preterm delivery wasn't significantly different in women pregnant after non-IVF ART. No association between IVF & risk of low birth weight at term or admittance to the NICU.	ART + NICU In Denmark, IVF is free. IVF pregnancies achieved after single embryo transfer also may have an increased risk of preterm delivery (doesn't fully explain the higher risk of preterm delivery with IVF pregnancy). The ^ risk of preterm delivery after IVF may be due to the

						fertility treatment or unknown characteristics in the couples who undergo IVF.
Gameiro, Moura-Ramos, Canavarro, Santos, & Dattilio. 2011. Congruence of the marital relationship during transition to parenthood: a study with couples who conceived spontaneously or through assisted reproductive technology. Portugal	To exam the congruence between partners' perceptions of their marital relationship during the transition to parenthood and the effect of depression during pregnancy on couples' congruence during the early postpartum period.	Infertility, ART, transition to parenthood, marital congruence, depression.	Longitudinal prospective study. N=66; 35 couples conceiving through the use of ART and 31 couples conceiving spontaneously.	Questionnaire at 24th weeks of pregnancy (T1), and 4 months postpartum (T2). Depression symptoms were assessed using Brief Symptom Inventory (BSI) scale. The marital relationship was assessed at the 24th week of pregnancy and 4 months after the partum. Data were analyzed using SPSS.	Infertility, ART, Transition to parenthood/ All couples reported a decreased in marital congruence. Couples who conceived through ART reported lower marital congruence. Women's depression was associated with lower congruence.	ART + parenthood. Study hypothesized that all couples would experience a decrease in congruence across their transition to parenthood, but it was estimated that this would be smaller for couples who conceived with ART compared with couples conceived spontaneously.
Ross, Mcqueen, Vigod, & Dennis. 2011. Risk for postpartum depression associated with assisted reproductive technology and multiple births: a systematic review. Canada	To address the knowledge gaps and identify directions for future research through a systematic review of studies reporting on rates of postpartum depression and/or	PPD, infertility, multiple birth, ART.	Systematic literature review. N=13 eligible articles were selected and reviewed.	Electronic databases were used.	Infertility, ART/ Little or no increased risk for PPD among women who use ART to conceive. Mother of multiples may be at increased risk for symptoms of depression.	ART + multiple birth. Hypothesis: women who conceived using ART and women with multiple births, may be at increased risk for PPD.

	severity of depressive symptomatology among women who experience conception through ART and/or multiple births.					Limitation: doesn't distinguish differentiation between transient maternal distress and clinically significant PPD.
Lee, Liu, Kuo, & Lee. 2011. Postpartum depression and correlated factors in women who received in vitro fertilization treatment. Taiwan	To evaluate factors associated with postpartum depression in women who received IVF treatment.	IVF, PPD, postpartum women.	Cross-sectional study using a convenience sample. N = 60 women conceived via IVF.	Beck Depression Inventory (Chinese version), Maternal Confidence Questionnaire, Family APGER Index, Interpersonal Support Evaluation List, Perceived Stress Scale were used. Data were analyzed with SPSS.	ART/ Pearson correlation analysis showed that the frequency of receiving IVF treatment and perceived stress were positively correlated with PPD, and family function and social support were negatively correlated with PPD.	ART + mental health. The number of IVF, birth methods, and social support were key factors with PPD.
McMahon, Boivin, Gibson, Fisher, Hammarberg, Wynter, & Saunders. 2011. Older first-time mothers and early postpartum depression: a prospective cohort study of women conceived	To evaluate whether older first-time mothers (>37 years) have higher rates of postpartum depression compared with younger first-time mothers, controlling for mode of	ART, maternal age, PPD, Psychosocial.	Prospective cohort study. N=592; nulliparous women who had conceived naturally (n=295) and women who had conceived through ART (n=297) from three age groups: 20-30y (n=173), 31-36y	Major depressive disorder (MDD) in the first 4 months after birth as assessed by structured diagnostic interview. Semi structured interviews and questionnaires.	ART, PPD/ Older first-time mothers, whether conceived through ART or spontaneously, do not show increased vulnerability to postpartum depression.	ART+ mental health. Trend toward older age at first birth may become the norm. High socioeconomic profile is characteristic of

spontaneously or with assisted reproductive technology. Australia	conception and known risk factors for postpartum depression.		(n=214), and older >37 (n=189).			older mothers and of women using ART to conceive, risk profile for MDD is low.
Warmelink, Stamrood, Paarlberg, Haisma, Vingerhoets, Schultz, & van Pampus. 2012 Posttraumatic stress disorder, anxiety and depression following pregnancies conceived through fertility treatments: the effects of medically assisted conception on postpartum well-being. Netherlands	To compare the postpartum prevalence of PTSD anxiety and depression in women who conceived via ART.	Anxiety, depression, IVF.	Cross-sectional study N=428 women that participated; 32 ART mothers and 396 non-ART mothers.	PTSD was measured with the Traumatic Event Scale-B; anxiety and Depression Scale. Asked mothers to complete questionnaires two to six months postpartum.	Infertility, ART, PPD/ No significant differences were found in the prevalence of PTSD (0.0% vs 1.3%; odds ratio [OR]=0.0, confidence interval [CI]:0-∞), anxiety (28.1% vs. 22.2%; OR=1.4, CI 0.6-3.1) and depression (9.4% vs. 14.6%; OR=0.6, CI: 0.8-2.0) between the 32 ART mothers and the 396 non-ART mothers.	ART + mental health
Darwiche, Lawrence, Vial, Wunder, Stiefel, Germond, Despland, & de Roten. 2014. Anxiety and psychological stress before prenatal screening in first-time mothers who conceived through IVF/ICSI or spontaneously. Switzerland	To compare the levels of general anxiety, anxiety specifically related to the well-being of the child, and psychological stress prior to non-invasive screening (the first trimester test) in future mothers who conceived through IVF/ICSI	Anxiety, pregnancy-related anxiety, psychological stress, prenatal screening, IVF.	N = 105 nulliparous women >24 years of age; 51 women who conceived through IVF or ICSI treatment compared to 54 women who conceived spontaneously.	The emotional states of the women were assessed through self-reported questionnaires (completed before or day of the antenatal first trimester test) evaluating general anxiety, anxiety about the child's well-being, psychological stress,	ART, parenthood/ Women who conceived through IVF/ICSI had more elevated levels of general anxiety and psychological stress than the women who conceived naturally. No difference was observed between the two groups for anxiety specifically related to the health of the child.	ART+ mental health

	with that of future mothers who conceived spontaneously.			and psychosocial stress.		
Listijono, Mooney, & Chapman. 2014. A comparative analysis of postpartum maternal mental health in women following spontaneous or ART conception. Australia	To determine whether conception following ART predisposes women to increased risk of postnatal depression, compared to women who conceived naturally, when controlling for such factors as: multiple birth, previous maternal psychiatric history and sociodemographic status.	ART, IVF, postnatal depression.	Women who attended private antenatal and fertility clinics of a fertility specialist in a large Australian city between January 2009 and December 2011 were contacted via phone. N = 189 (94 ART & 95 natural conception) women participated.	There was no difference in the rate of postnatal depression (PND) between the two group (p=ns). There was a significantly higher rate of previous mental clinical depression in the ART group compared to the controls (p <0.05). However, previous PND, multiple birth, and low infant birth weight were not different in the two groups (p=ns). In addition, non-ART women were more likely to breastfeed for a longer duration (p <0.05).	ART/ There was no difference in the rate of PND between the two groups (7.5% versus 7.4%, p 1⁄4 ns). Women who conceive using ART are not at an increased risk of PND. There was a significantly higher rate of previous maternal clinical depression in the ART group compared to the controls. Other known risk factors for PND, including previous PND, multiple births, and low infant birth weight, were not different in the two cohorts.	ART + mental health Women who conceived naturally were also more likely to breastfeed for a longer duration
Raguz, McDonald, Metcalfe, O'Quinn, & Tough. 2014. Mental health outcomes of mothers	To compare the proportion of women with self-reported depression and anxiety symptoms	ART, IVF, postpartum depression, anxiety, fertility treatment.	N=1296 women as final sample size to analyzed. • study group, which used ART (n=76).	The data was collected via three questionnaires, two of which were mailed to the participants during	ART/ At four months postpartum, the proportion of women who experience elevated symptoms of	ART + mental health

who conceived using fertility treatment. Canada	at four months postpartum between mothers of singletons who conceived spontaneously and mothers who conceived with ART treatment.		• control group (n=156) were randomly selected from 1220 non-ART women. • Samples were selected from a community-based prospective cohort of pregnant women who received prenatal care in Calgary, Alberta.	pregnancy (18-24 weeks and 34-36 weeks) and one at 4 months postpartum. Symptoms of depression and anxiety during pregnancy and at four months postpartum were measured using the EPDS, the Spielberger State Anxiety Inventory and Perceived Stress scale. To evaluate parenting moral, the Parenting Moral Index was added in the postpartum period.	depression, anxiety or perceived stress do not differ between mothers who conceive using fertility treatment and those who conceive spontaneously. Parenting morale at four months postpartum is significantly lower in primiparous mothers conceiving spontaneously compared to those who conceive with fertility treatment.	

USA Studies

Authors, Year, Title Country	**Purpose of Study**	**Key words**	**Methods/ Design/ Sample**	**Measure/ Intervention**	**Concept/ Findings**	**Comments**
Klock, 2004. Psychological adjustment to twins after infertility. USA	Hypothesized that mothers of twins who have history of infertility would be at increased risk for	Infertility, twins, postpartum depression, marital adjustment,	No applicable – this was a review of the literature without a literature matrix nor any indication of inclusion or	Literature review	Infertility, Parenthood/ Infertile couples desire multiples but have a limited understanding of the demands of multiple parenting;	ART + twins+ Mental health

	depression and marital decline.	multiple pregnancy.	exclusion criteria used by the authors providing rationale for selection of articles. It was neither a study or a comprehensive, integrated review and synthesis of the articles.		10% of women develop PPD & marital adjustment declines.	
Shin, & White-Traut. 2007. The conceptual structure of transition to motherhood in the neonatal intensive care unit. USA	A report of a concept analysis of transition to motherhood for mothers with infants in a NICU.	Concept analysis, interviews, motherhood, NICU.	38 studies were reviewed and 10 Korean mothers with NICU infants were recruited from university hospital in Korea and semi-structured interviews were conducted.	Concept analysis study of transition to motherhood using Rodgers' evolutionary method	Parenthood/ Mothers of NICU babies are often delayed establishing motherhood	NICU + motherhood
McQuillan, Stone, & Greil. 2007. Infertility and life satisfaction among women. USA	To explore the association between lifetime infertility and life satisfaction among women.	Infertility, internal medical locus of control, life satisfaction, life course, motherhood.	N= 196 women from 12 states in the upper Midwest.	Used a scale created by Diener and Diener (1995) that has desirable psychometric properties across a variety of ages to measure life satisfaction. The structured interview (background characteristics, fertility status, pregnancy history,	Infertility/ Of the women included, 69 perceived fertility problems, and 127 women did not perceive any problems. No direct correlation between lifetime infertility and life satisfaction, regardless of a woman's perception of fertility problems. However, the result indicated that there is a strong association	ART + mental health (life satisfaction) They also found that employment ameliorates the strong negative association between infertility (compared to no infertility) and life satisfaction for non-mothers.

				help-seeking behavior, and social psychological outcomes)	between motherhood and marriage (r=.30, p<0.001)	
Choi, Bishani, & Minkovitz. 2009. Multiple births are a risk for postpartum maternal depressive symptoms. USA	To assess the relationship between multiple births and maternal depressive symptoms measured 9 months after delivery.	PPD, multiple births, screening.	A longitudinal study of a nationally representative sample of children born in 2001. N = 8069 mothers (7293 singleton and 776 multiple) included this study. Data were derived from the Early Childhood Longitudinal Study-Birth Cohort. Three sources were used for analysis; • A parental self-administered questionnaire • Interview at 9 months of age • Birth certificate	Maternal depressive symptoms at 9 months after delivery were measured using Epidemiologic Studies Depression Scale (CES-D).	ART/ Mothers of multiple births had greater odds of having moderate/severe, 9 months PPD.	ART + mental health. Parental stress in raising multiple infants is primary cause of maternal depression. No direct causal relationship between PPD and neurobiological factors, little information is available regarding the magnitude and duration of hormonal changes and dysregulation associated with multiple births.
Lynch, D. C., & Prasad. 2014 Association between infertility treatment and symptoms of postpartum depression. USA	To exam the association between infertility treatment and subsequent symptoms of postpartum depression.	Infertility treatment, IVF, postpartum depression.	Cross-sectional study N=40,337 women responding to questionnaires from the CDC Pregnancy Risk Assessment	Main outcome measure: Odds of symptoms of PPD.	Infertility/ In a population-based sample of U.S. women, conceiving with ART didn't increase the odds of experiencing symptoms of PPD.	ART + mental health

			Monitoring System (PRAMS).			
Lewis, Liu, Stuart, Ryan. 2013. Less depressed or less forthcoming? Self-report of depression symptoms in women preparing for in vitro fertilization. USA	To examine response profiles in women preparing for IVF, and compare responses to those of postpartum, primary care, and general population groups.	Depression, infertility, screening, IVF.	Retrospective chart reviews that identified 419 women or couples that were new IVF patients at the study site.	Participants completed the PHQ-9 at their first visit. 321 of the 419 patients completed the PHQ-9 screening tool.	ART/ Women preparing to undergo IVF report fewer symptoms of depression than other comparison groups.	ART + mental health Small sample size. Specific quality of life measures may be needed to assess distress in this population.

Appendix B

Consent Form

Agreement of Participate in
"Inquire postpartum mental health of ART mothers with NICU babies"
Kiyomi Oshiro
(808) 956-8552
School of Nursing and Dental Hygiene PhD Program
University of Hawai'i at Mānoa

This study is being done as part of my doctoral program at the University of Hawai`i at Mānoa School of Nursing and Dental Hygiene. The purpose of the study is to understand the experiences and thoughts of first-time mothers who received an assisted reproductive technology (ART) treatment and who then gave birth to infants needing care in the neonatal intensive care unit. You are being asked to participate in the study because you are a mother who received an assisted reproductive technology treatment to become pregnant and then had your baby taken care of in the neonatal intensive care nursery at Kapiolani Medical Center for Women and Children.

Your participation in the study will consist of filling out a short form with questions about you and then interview with the researcher that will take place approximately two to four weeks after your baby is discharged from the neonatal intensive care nursery. The interview questions will ask about your experiences and thoughts about having your baby in the neonatal intensive care nursery. The information from the interview will be reviewed by me and my doctoral advisor, Dr. Maureen Shannon (a faculty member at the Department of Nursing at the University of Hawai`i at Mānoa), to determine experiences and thoughts that are common to mothers who participate in the study. The completion of the form should take no more than 5 minutes, and the interview will last about one hour. The interview will be audio recorded with the information on the tape then typed up for my being able to review what you have shared and compare it to other mothers.

Your participation in this study may be of no direct benefit to you. However, it is possible that the results from this study may help healthcare providers to provide better care to mothers like you with infants who were in the neonatal intensive care unit. The results may add to doctors and nurses understanding of what additional support systems are needed for mothers in the same situation as you experienced.

The study information that is collected will be confidential. A study identification number will be used to identify each mother participating in the study. All of the informed consent forms and study documents will be kept in a locked file that only the researcher can access. The information about you that is collected on the form and during the interview (e.g., tape recordings, researcher's notes) will be kept separate from the informed consents. If any of the research results are published, the mothers who participate in the study will not be identified in any way.

Your participation in this study is completely voluntary. You are free to withdraw from the study at any time and no penalty or loss of any benefit to that you would otherwise be entitled.

Participant:

"I certify that I have read and that I understand the foregoing, that I have been given satisfactory answers to my inquiries concerning project procedures and other matters and that I have been advised that I am free to withdraw my consent and to discontinue participation in the project at any time without prejudice.

I here with give my consent to participate with an understanding that my identity will remain anonymous in this project. I also understand that such consent does not waive any of my legal rights, nor does it release the Principal Investigator or the institution or any employee or agent thereof from liability for negligence."

_____
Name (printed)

_____ _____
Signature Date

_____
Name (printed) of person obtaining consent

_____ _____
Signature of person obtaining consent Date

Please contact the primary researcher Ms. Kiyomi Oshiro at oshiro@hawaii.edu or Dr. Maureen Shannon at maureens@hawaii.edu if you have any questions regarding this project. If you cannot obtain satisfactory answers to your questions or have comments or complaints about your treatment in this study, contact: Committee on Human Studies; Telephone: (808) 956-8480; E-mail address: uhirb@hawai.edu

Appendix C

Demographic Data

1. Maternal age
   <30 y
   30-34y
   35-39 y
   >40y

2. Marital Status
   Married
   Single (not living with partner)
   Widow
   Separated
   Living with partner

3. Infant's gestational age at birth
   22-26 wk
   27-30 wk
   31-34 wk
   35-37 wk
   >38 wk

4. Maternal ethnicity/race
   White
   Black
   Asian (please specify)
   Native American/Alaskan
   Native Hawaiian/ Pacific Islander
   Hispanic
   Non-Hispanic

5. Highest level of education
   Some high school (did not graduate)
   Graduated high school
   Associate degree or some college
   Bachelor's degree
   Master's degree
   Doctorate (PhD, MD, JD, DrPH, EdD, etc.)

6. Geographic location of residence
   Honolulu
   North Shore Oahu
   Central Oahu

Windward Oahu
Leeward Oahu
Kauai
Maui
Hawaii
Lanai
Molokai
Other U.S. states
Other country

7. Pregnancy history (please circle if you had experienced)
Multiple infants (twins, triplets, etc.)
High Blood Pressure
Preeclampsia
Preterm labor
Water broke before onset of labor
Placenta problems
Others

8. Type of assisted reproductive procedure
Medication only
In-vitro fertilization (IVF)
Gamete intrafallopian transfer (GIFT)
Pronuclear stage tubal transfer (PROST),
Tubal embryo transfer (TET)
Zygote intrafallopian transfer (ZIFT)
Intra-cytoplasmic sperm injection (ICSI)
Intra-uterine insemination (IUI)

9. Previous pregnancy loss
No
Yes (if yes, please provide more information)

Appendix D

Interview Guide

1. Please share with me what it was like for you to have your baby in the neonatal intensive care nursery.
2. What were the ways that you coped with having your baby in the intensive care nursery?
    a. What helped you the most to cope?
    b. What seemed to make it more difficult for you to cope?
3. Can you share with me any thoughts that you have about your having had IVF and then having your baby needing care in the intensive care nursery?
4. Is there anything else that you would like to share about your experiences?
5. Can you tell me what your thoughts are about participating in this study?

Probes

Can you tell me some more about that?

Can you clarify that some more for me?

Appendix E

Codes Definitions

Participant #	Codes	Description/ quotes	Thought/ memo
1, 2, 3, 4, 5, 6, 7, 8	1. "Scary" -in vivo	Scary to be discharged (responsibility to take care of baby at home) Scary when babies came out that early (preterm delivery@ 25wk) Scary to see treatment in the NICU (in the incubator with monitor and IVs.) Scary to handle baby with IV Feeling of fear all that time Baby's condition change scares the most Having identical twins was scary Scared not knowing unknown things Always scared we might lose the baby Very scary at night with baby at home (couldn't sleep) Scared to take care of the baby at home, used home monitor for assurance Alarm (monitor) was scary Always felt something might happen (feeling of being scared all the time)	Intense sense of being scared and vulnerable All experiences in the NICU were simply too scary Hx of infertility and complex pregnancy may affect intensity of feelings of being scared Sense of being scared due to unknown experiences and place (i.e., NICU) Always felt something might happen (feeling of fear all the time) when not with the baby Uncertainty for baby's outcome creates fear for mothers
1, 4, 5, 6	2. Routine	Developing routine(s) helped us cope with the NICU experiences Developing (following) routine(s) helped transition from the NICU to home Without a routine, it was nerve-wracking	Routine helped coping and made things more comforting in the NICU, also including transition from NICU to home
1, 2, 3, 4, 5, 6, 7, 8, 9	3. Uncertainty	Felt she would never be pregnant Couldn't choose selective reduction (triplets) because of increased risk of losing all embryos; and also, did not choose an amniocentesis in order avoid any risk (i.e., aborting) Length of NICU stay Unknown about future (of infant) Unknown infant's condition and developmental status Scared because of unknown things that might develop	Uncertainty begin pre-pregnancy May be last chance for woman to have her own baby Did not want to take any risk contributing to potential loss of pregnancy (uncertainty of the outcome) Not knowing and uncertainty increase mothers' anxiety

		"Jinx"- waited to have a baby shower until it was planned to happen closer to the baby's discharge because didn't want to be disappointed if the baby's NICU discharge was postponed Terrified that unknown things may happen	Difficult pregnancy creates more anxiety in any situation, including pregnancy, the NICU stay. Try not to expect things to happen as planned (be realistic). Hx of loss of one of her twins 24 hours after the twins' birth
1, 2, 3, 4, 6, 7, 8, 9	4. Feeling cared for	Felt that the baby is "in good hands" Relief knowing someone was monitoring the baby (sense of good care) Establishing trust -> mother feels more comfortable with baby's safety Baby was well cared for Parents felt cared for when greeted by the NICU staff Weekly phone call by nurse through HMSA program made me feel cared for after we were discharged Knowing someone will always be there for us Being involved in the doctor's rounds felt "special" (talking only about her own babies)	Trust that NICU staff was providing good care for infant eased maternal anxiety Reassurance created comfortable feeling and created sense of support Being acknowledged/recognized by others was helpful and made the mothers/parents feel taken care of by NICU staff
1, 2, 3, 4, 5, 6, 7, 8, 9	5. Unknown	Seeking information about what mother does not know (or understand) Using medical terminology contributed to a sense of unknown Unknown criteria for the NICU admission (mother needed more information about this)	Trying to understand what's going on when it was not clearly conveyed

1, 2, 3, 4, 5, 6, 7, 8, 9	6. Anxious	Anxious about baby's treatment in the NICU Language barrier contributed to anxiety due to not being able to understand all that was happening in the NICU Anxious due to not seeing babies immediately; physically staying with baby eases anxiety All of the time in the NICU was worried that the baby might die Always worried something bad might happen to the baby (in the NICU) Prayed during the whole pregnancy due to being worried that something might happen to the unborn baby Anxiety due to separation from infant Anxious having identical twins Worried if baby will need special therapies for developmental issues due to being born as a premature baby Always worried about everything about the baby during pregnancy Nervous assuming care of baby when first at home Anxious to take baby home Anxious about lack of knowledge about reasons for delayed discharge Home monitor for the baby helped relieve anxiety	Several similar words were used such as anxiety, nervous, worried Sense of uneasiness and concern about the situation; nervousness Having contact with infant and seeing evidence of improvement helped decrease anxiety Not able to control "if" situations led to more anxiety Language barrier increased anxiety Not having developed a trustful relationship with medical members (distrust increased anxiety) Separation from the baby increased anxiety
1, 2, 3, 4, 5, 8, 9	7. Unexpected experiences	Unexpected experiences Unexpected premature delivery (25wks) Emergency C-S Wasn't the same as what was expected Unexpected to have infant admitted to the NICU Crazily busy taking care of both twins at home (unexpected how demanding taking care of infants was) Difficult to feed both of them at the same time Complication of the delivery Didn't expect separate discharge of the twins	Mentally, physically was not prepared No sign of miscarriage creates more anxiety during pregnancy (sense of may happen again) Being a first-time mother (because of infertility problem)

1, 2, 3, 4, 5, 6, 7, 8	8. Maternal expectation	Expectation of normal pregnancy Expected (predicted) short stay in the NICU Planned a normal delivery Expected that it may be a difficult delivery due to twins Anticipated a healthy baby (term baby) Expected to have a premature delivery Expected that the baby might need a NIUC admission Expected having a CS but one that was scheduled and not an emergency CS Happy to deliver the babies at 34 weeks as healthy babies even being premature babies (felt better than having medical issues)	Negative image of the NICU Researched what to expect to be prepared Trying to prepare for the future both mentally and physically
1, 3, 4, 5, 6, 7, 8, 9	9. Emotional preparations	Informed possible NICU admission, but wasn't prepared Researched information in order to prepare for possibility of problems Prenatal consultation from the neonatologist before delivery helped to prepare for possible NICU stay Tried to prepare for the worst-case scenario Was lacking preparation for the NICU admission (no one informed them about the possibility of this) Lack of preparation (short notice) Lack of preparation for infant care Felt NICU stay reassured babies' readiness for discharge "One thing at a time" One day at a time (after infant's birth) "No rush," became patient (result of IVF experience) "Nothing could prepare"	Hard to prepare for the NICU without previous experiences with or information about being provided by medical team Majority of participants indicated that they weren't informed by OB doctor about possibility of NICU admission The NICU tour may help to prepare Encouraging mom to take infant care class in early pregnancy may help IVF experience results in being patient No rush to be discharged Focusing on one thing at a time may help reduce anxiety and contribute to feelings of competence in infant care or decisions about infant

1, 2, 3, 4, 5, 6, 7, 8, 9	10. Knowledge	Discovered information about physical signs from infant's daily care Learned from nurses involved in infant's care Information helped mothers/parents cope Seeking information/knowledge Information and knowledge helped understand the infant's treatment and medical decisions of NICU team "Information and knowledge is very important" Not necessary to inform in advance because "anything might happen" Did her own research about the risk factors such as advanced maternal age NICU stay was an educational period (preparation for the care of infants when transitioned home) "MD rounds were the best information" Practice (hands-on care for the baby) makes perfect Don't know of anyone whose infant was admitted to the NICU Had no idea about possibility of NICU (no one informed her) Sharing experiences with other NICU mothers increased knowledge March of Dimes activity provided information—increased knowledge Disagreed with the care and treatment the medial team recommended (felt unnecessary to insert the infant's NG tube)	Learning process Knowledge helped mothers/parents **cope** better Gaining confidence to take care of the baby Gaining knowledge through medical team and nurses Being involved in MD rounds was perceived as an information session for mothers/parents Self-research helped to prepared mentally and physically for possibilities Lack of knowledge creates conflict with medical team regarding the treatment (Conflict with medical team due to disagreement regarding the treatment because of parental intuition)
1, 2, 3, 4, 5, 6, 7, 8, 9	11. Physical distance	Distance from the hospital created stress (e.g., driving in traffic, long distances) and less sleep Distance from the hospital also created time management issues such as time commuting to the hospital: less sleeping time, not enough time to pump breast milk, which created less milk production and not enough breast milk for infant Physical access to the NICU was convenient with the new wing of the hospital "Couldn't stay (in the NICU) all that time" "Didn't want to miss any moment with the babies" Contributed to having infant bonding issues Unit's overflow created physical distance (couldn't stay in the room with the baby overnight)	Less physical contact with the babies after delivery No bonding time with the baby right after the delivery due to the NICU admission process Physically incapable (post CS) to visit babies Needed to spend more time with baby from the beginning to establish connection with the baby which also creates confidence to take care of baby Many mothers stated that wanted to stay with baby all that time Commute between home and hospital also created "distance" and difficulty for time management such as pumping

		Busy with the daily life (commute to and from hospital to visit babies)	
1, 2, 3, 4, 5, 6, 7, 8, 9	12. Physical environment	Whole new environment for mother's baby and family Create own "team" NICU was a foreign environment Exposed to the technology (IVF treatment, NICU treatment) Private room was comfortable environment for infant and parents NICU was a safe environment for infant (i.e., protected from other people, diseases) Having the space in the private room Private room was comforting Felt secure in the NICU (ID band, barcode to enter NICU) Infection control in the NICU was good (wash hands, alcohol sanitizer) NICU stay provided reassurance about babies' conditions Felt lonely in the dark room (didn't like the "quiet time") Felt it (NICU) was the best place for the infant Right birth timing, right place Seeing medical intervention in the NICU was difficult Positive experience about the NICU stay (appreciated) Could recover from giving birth while babies were in the NICU Felt the NICU was family-centered Staying in the room with babies was huge factor (less physical distance from them) Meal coupons helped me/us in the NICU Familiar nurses, other staff (RT, OT, ST) and medical team in the NICU environment Becoming familiar with infant's care in the NICU How to care for self while baby in the NICU	Unique environment Multiple people and technologies involved—so becoming used to the environment was necessary Privacy was important Didn't have to worry about others' judging them Options for parents to remain with infant (family-centered) No need to see unwanted things with other babies Able to focus on own baby in a private room Happy with the treatment of the baby General experience in the NICU was positive Overall experience was good Became open-minded with the NICU experience Reassured that this was the best unit for the babies Felt secure to be in NICU and discharged from NICU Reassured by care in the NICU Understood the necessity of the stay and treatment even though stressful Mother/parent's becoming familiar with new environment and medical stuff was important

1, 3, 4, 5, 6, 7, 8, 9	13. Transition being a mother	In-hospital infant care classes helpful with transition to home Difficult to have normal transition to motherhood to begin with because of separation from the baby Time away from work was helpful for the transitions needed NICU stay and treatment reassured (mother) about babies' readiness for discharge Eager to take babies home (confident to take care of babies at home) Scared to take baby home after spending couple months at the NICU Wanted to take twins at the same time It ended up being good (helped) to take one of twins home first because couldn't imagine how busy it was taking care of twins at home	Adjusting to the new environment and roles After baby discharged to home, kind of a shock about baby's behavior (e.g., fussiness, etc.) Staying overnight in the NICU helped with the transition The longer the time spent in the NICU the more difficult the transition to the home Taking care of twins at home is very busy and difficult time management
1, 4, 6, 7, 8, 9	14. Consistency	Having consistent medical team (doctors, nurses, other personnel) was important; consistent information also important Consistent routine was helpful Inconsistency of medical team contributed to stress and anxiety Confused about inconsistent information Exposed to unfamiliar medical team (i.e., not a consistent team) Inconsistency about the treatment/information Nervous about meeting new medical team every few weeks (medical team rotation) Having a different nurse for each of the twins (separate assignment) Having different nurses, doctors	Having the same NICU team helped decrease anxiety Extended time with the same staff built confidence and established relationship Continuity of care givers helps build trust and rapport Feeling of distrust due to Hx of miscarriage (felt no one listen to me, wasn't individualized treatment) Too many doctors' opinions with some different information Each doctor had a different philosophy and strong opinions—not the same among the doctors
1, 2, 3, 4, 5, 6, 9	15. NICU nurses	Rely on nurses in the NICU (for baby's special care) Used as the resource Nurses' advice was helpful Learned infant care through nurses Experienced NICU nurses were important Discomfort with inexperienced nurses	"Primary nurses" had a big role (made it easy, decreased anxiety, helped cope with NICU) Nurses encouraging mothers to do hands-on care, teaching was important Relationship with nurses was important to develop trust, ease mother's feeling Consistency of seeing same faces made mothers feel at ease and comfortable

1, 2, 3, 5, 6, 7, 8	16. Breastfeeding	Desired versus no desire for exclusive breastfeeding Breastfeeding was hardest thing in the NICU Felt pressure to breastfeed (felt no choice) Challenged about breastfeeding the infant Difficulty breastfeeding (was stressful?) Hard to choose which one (of the twins) to breastfeed or bottle feed Stressful moments (when trying to breastfeed) Breastfeeding (hardest experience in the NICU and even after discharge from the hospital) To do exclusive breastfeeding (not enough breast milk for both of the twins) Felt pressure to exclusively do breastfeeding, was hardest part in the NICU experience (create lots of guilt and doubt) Felt no other options were provided—no choice regarding some issues (breastfeeding) Seeking resources after discharged from the NICU	Lactation consultation helped Overwhelming to have lactation consultants (stressful moments) Less stress at home for the feeding (because she has a choice—sense of autonomy) Feeding in the hospital created anxiety Struggling with breastfeeding even after discharge This comment was an eyeopener that someone actually felt pushed/uncomfortable about breastfeeding
1, 6, 8	17. Emotional rollercoaster	Emotionally up and down Small things had a huge effect (baby's weight gain [happy], weight loss [sad]) "bump in the road" (i.e., NICU admission after IVF) One day happy and another day felt sad (babies in the NICU) Having IVF treatment was more of an emotional rollercoaster Contradictory emotions	Happy once pregnant but mentally will never be free of worry because of uncertainty of outcomes Baby's condition affected mother's mental health (ups and downs) Psychologically labile due to uncertainty about infant's health, treatments, and length of stay in the hospital.

1, 2, 3, 4, 5, 6, 7, 8, 9	18. Support systems	Family members (mother's own mother and sister) Husband's support important to cope March of Dimes' services were helpful and supportive Talking to other NICU parents Self-care is important (Husband helped me to think about it) Limited support system because there were no family members around "No support group for me during infertility treatment process" Sharing the experiences with family members was important To be open to someone released pressure Felt good about sharing the experiences with someone Wanted personal interaction with someone who has the same experiences Relationship with a doctor focused only on medical things and not emotional or psychological issues (not supportive) Counseling by psychologist Talking to other NICU mothers March of Dimes activities	Emotional/physical support from family members (own mother and sister) is important to help cope Learning from others' experience in the NICU (provided support and assured them that they were not the only ones experiencing this situation) Didn't have normal thinking process Wanted to feel being supported Mental status affected treatment outcome Somewhere needed to have a way to vent feelings/experiences (needs a support group in the community) Support systems were part of coping mechanism
1, 2, 3, 4, 5, 6, 7, 8	19. Treatment in the NICU	Tube-feeding was the hardest thing to see in the NICU Happy with the care in the NICU Not pleasant to see babies having NG tube and IV insertions Terrified with the treatment Seeing medical intervention was difficult Felt sad that baby needed to have some treatment and/or procedure "If no IVF treatment, it could have been a more horrible experience being in the NICU"	Felt sorry for babies due to the treatments the mothers witnessed them having in the NICU but accepted the necessary treatment Easier acceptance of using NICU technology for infants' treatment (e.g., history of IVF treatment increased mothers' comfort with the technology used in the NICU)

1, 2, 3, 4, 5, 6, 7, 8, 9	20. IVF experiences	Disappointed with many failing results (of IVF) Learned to be patient (due to hx of many IVF treatment failures) Exhausted about the treatment (mental & physical burden) Treatment was emotional ("excited it's going to work and then feeling it never will") "Mentally, emotionally and physically hardest things ever" "One of the hardest times in the life" Felt it should be individualized treatment (but it wasn't) Infertility treatment was terrible experience (negative effects on relationship with partner, mother's self-esteem) Felt as if she was a failure as a woman "Professionals should have understood and need to be more sensitive about what the female going through" "Fertility as winner and infertility as loser" "Infertility means God is telling you that you shouldn't be parents" Infertility treatment like being at war (feel PTSD) During the infertility treatment period, woman felt alone and sad Felt badly for her husband Cognitive therapy for self was needed Disappointed to have monthly period after IVF attempts Positive experiences after first attempt resulted in good relationship with OB team Trusted OB doctor because friend had positive experience with same doctor Distrust with the medical staff because "they didn't listen to my opinion" Trying to get pregnant was much harder than being in the NICU Regretted putting career first Didn't realize time limit for optimal fertility and chances to become pregnant	Avoiding disappointment may be important Due to hx of many failings, worried continuation of the pregnancy after became pregnant Having strange feelings about being pregnant because they felt that they would never be pregnant (due to waiting so long to become pregnant and having to go through IVF to succeed in conception) Burdensome experience Mental healthcare seemed to be important during the process Successes with first IVF attempt makes the woman feel "lucky" (didn't need to undergo more Tx) Someone felt lack of emotional support by medical team Repeat IVF cycles – possibly resulted in better coping with NICU experiences Lack of "voice" during IVF Establishing trust with OB team-> makes mother more comfortable with treatment; contributes to establishing trust Conflict with women's career versus advance maternal age limitations

5, 6, 7, 9	21. Ideal vs. reality	Feeling guilty when having to leave hospital without the baby Felt guilty because she couldn't be there (NICU) all the time Hard to choose which twin to breastfeed—couldn't breastfeed both Felt guilty not doing exclusive breastfeeding Angry because she couldn't see her babies immediately after birth Missing babies ("felt pulling inside of me") Aggravated while awaiting to see her babies "No words when I saw them for the first time. Best day ever." "Upset that I couldn't take both babies home at the same time, but it ended up, it was better to take one baby home at a time." "it was not the experience that I thought it would be" Disbelief about actually being pregnancy	Create guilt and doubt if didn't fit ideal situation (or what the majority of people think/expected) Felt NICU admission was unnecessary but immediately resolved when saw the baby Felt beside herself when saw babies for the first time Reality of care for the NICU baby transitioning home was different from the mother's ideal picture
3, 6, 7, 8, 9	22. Complexity of the pregnancy	Experience of miscarriages Tried alternative methods Experience of ectopic pregnancy Whole pregnancy was hard (hx bleeding and bedrest for a while) Hx of threatened abortion Hx of preterm labor Bedrest for 2 months PTSD like emotional damage from miscarriage and D&C	Long time waiting to become a pregnant after experiencing previous pregnancy loss Not only difficulty to become a pregnant but also difficulty to carry baby to full term Majority of participants were having multiple gestations (consequence of infertility Tx) Traumatic experience with miscarriage and D&C leads to make decision to have IVF (with donor egg)

1, 2, 3, 4, 5, 6, 7, 8, 9	23. Difficult moment	To see the baby's regression of status Medical team's rotation (every few weeks): receiving different opinions Nurses' attitude affects emotionally (difficult moment) Seeing friend's pregnancy to full term was hard Difficulty seeing NICU "neighbor" being discharged before her baby Had to depend on nurses to take care of the babies (twins) in the NICU Wanted information/advice but not instruction (wanted to be a competent mother) Did not like to be told what to do about the baby Felt pushed by doctors' own beliefs and philosophies without being able to have hers appreciated Felt "depressed" (felt like postpartum depression) after finding out the babies needed to be admitted to the NICU	Need to consider individual lifestyle (working women having twins) Create sense of not cared for enough Felt missed out the stuff (preterm delivery) Incomplete pregnancy period Control issues No autonomy Need to give "professional" advice/opinions but yet leave choice to mother/parents Individual approach for each family is needed Impact on the mental status of mom with NICU admission
1, 2, 3, 4, 5, 6, 7, 8, 9	24. Gratitude for "miracle" babies	Grateful for the baby's presence in her life Having kids was most important—mother forgot about the hardness of the treatment Felt supported for everything (right timing to deliver babies even though premature) Otherwise babies are healthy—premature but without deformities Happy to have a baby now Grateful when she held her baby for the first time Amazing (to have her own baby) So happy to see the baby for the first time in the NICU, was walking on air "They are miracle babies" "Feel fortunate to have my babies" "Happy to have my own baby now"	The mothers' dreams came true Happy about outcomes because of having a baby Reward for enduring the hardship of infertility treatment Gratitude to have her own children All participants looked happy (researcher's observation) Satisfied with outcome—grateful that infant is doing well Happy ending
1, 2, 3, 4, 5, 6, 7, 8, 9	25. Altruistic perspective	Doing things to help others (i.e., being in the study) Important to have the research about this issue, knowing someone was looking into this more made her feel happy to be part of the study Looking forward to seeing the article about the results of the study "I am happy to have a baby now, so I'm happy to help others"	Happy outcome contributed to being willing to participate in the study Willing to share their experiences in order to educate and help others

Appendix F

Codes, Categories and Themes

Themes	Categories	Codes
Fear of uncertainty	1. Anxiety	• Anxious (9) • Scary (8)
	2. Uncertainty	• Uncertainty (9) • Unknown (9)
A whole new world	1. Psychological preparation	• Unexpected experiences (8) • Maternal expectations (8) • Emotional preparation (8) • Emotional rollercoaster (3) • Difficult moment (9)
	2. Physical environment	• Physical environment (9) • Treatment occurring in the NICU (8) • Ideal vs. reality (4) • Routine (4)
Gaining knowledge as copying mechanisms	1. Support	• Feeling cared for (8) • Support system (9) • NICU nurses (7)
	2. Information	• Knowledge (9) • Consistency (6)
Journey to become mothers	1. Maternal-child attachment	• Physical distance (9) • Breastfeeding (7) • Transition to be a mother (8)
	2. Consequence of infertility	• IVF experiences (9) • Complexity of the pregnancy (5) • Altruistic perspective (9) • Gratitude for miracle babies (9)